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Los Angeles

Navigating the Transition to Adulthood: Perspectives of Autistic Individuals

A dissertation submitted in partial satisfaction
of the requirements for the degree Doctor of Philosophy
in Education

by

Samara Merav Wolpe

2025

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ABSTRACT OF THE DISSERTATION

Navigating the Transition to Adulthood: Perspectives of Autistic Individuals

by

Samara Merav Wolpe

Doctor of Philosophy in Education

University of California, Los Angeles, 2025

Professor Jeffrey J. Wood, Chair

Background: The transition from adolescence to adulthood is a formidable time for autistic* young adults. Poor health outcomes, low employment rates, and unfavorable independent living outcomes for autistic adults (Cimera & Cowen, 2009) make essential that the transition from high school to the next step of life be as frictionless and supported as possible. Despite the importance of this research, only 3.5% of published research involving autism focuses on adults (Howlin & Magiati, 2017). Only 2% of autism funding in the U.S. is allocated towards adult research in autism (Shattuck et al., 2020). Given the sparse nature of adult autism research at the present time, an exploratory approach was taken to highlight the present climate of young autistic adults transitioning into adulthood, emphasizing their lived experiences through interview data. This study addresses the following research questions: 1. What are the barriers

autistic individuals encounter in the transition to adult life? 2. What resources do autistic individuals find most helpful in navigating this transition? 3. What could families, organizations, employers, and educators do to support autistic adults transitioning into adulthood? 4. What strategies for success do participants recommend to autistic emerging youth to navigate the transition into adulthood? 5. What does success mean to autistic individuals in their own lives?

Objective: Participants were recruited primarily through social media, and secondarily through an organization that specializes in facilitating careers in the arts for autistic individuals.

Seventeen semi-structured interviews lasting between 30-60 minutes with autistic adults on the topic of transition into adulthood were conducted. This study aims to elevate autistic voices, further understand their experiences, and improve future outcomes for autistic transition-age youth through the lived experiences of the community.

Methods: Seventeen participants were recruited through social media and personal networks. Prior to scheduling an interview, participants were sent a consent form for review and a demographic questionnaire to determine eligibility. Interviews were conducted over Zoom and recorded. An inductive coding process was utilized, deriving codes from recurrent topics in the transcripts and iteratively returning to transcripts to form themes. A systematic coding consensus approach, following the framework proposed by Willms and colleagues (1990), was then employed. Two coders coded the transcripts separately, and subsequent discussions were held to reach consensus on any discrepancies. This iterative process allowed coders to construct a robust coding system and achieve agreement between raters. The software Dedoose (Dedoose Version 9.0.23) was used to facilitate the analysis of the data.

Results: Data analysis yielded several overarching themes: Educational/Vocational Experiences after graduation, Barriers to Success, What Worked to promote success in this life stage, and

Recommendations to various people and institutions that could promote better outcomes in future generations of transition-aged youth. Each of the major themes contained subthemes.

Conclusions: The results of this study inform future community-based interventions and the creation of more inclusive educational and workplace environments. This research further serves to elevate voices of the autistic community in promoting success in adulthood for this population and in creating a more inclusive future.

** **Language Statement:** The language ‘autistic’ is used throughout this paper when referring to individuals on the autism spectrum to respect and utilize the language preferred by the majority of autistic individuals (Taboas et al., 2023).*

The dissertation of Samara Merav Wolpe is approved.

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you have inspired me, driven me, and convinced me that I should spend my life making the world a better place for you and the autistic community. Thank you for opening your world to me and teaching me that there are other wonderful, beautiful, diverse ways of being human. Thank you to Lucas's family, who have supported and encouraged me on this path. Thank you also to all of my friends and coworkers at Spectrum Laboratory for creating a place I could unwind, be myself, be in autistic community, and always be reminded of why I cared enough about this topic to go to graduate school in the first place.

I also want to thank my wonderful friends, Robyn and Daniel. Robyn, you ensured that I was well-dressed for every meeting and major event, and that I did not get overwhelmed and sucked into being a work drone by inviting me to fun events, laughing with me, sharing stories, and being the best friend I could wish for. Daniel, throughout this program, you always expressed interest and curiosity in my work and were a person with whom I knew I could talk about my interests and always find a willing ear. You expanded my friend group so many times that nearly everyone I know is traced back to you and are you one of the people I feel that I can count on most in the world. Thank you for being a constant support and a wonderful friend in every way.

I next want to thank my incredible parents, who each deserve their own individual thank yous, but I will start as a collective. You both have made it clear to me since I can remember that who I am is enough and that I didn't need to do anything to prove my worthiness to you. Well, here's a dissertation. I always did like extra credit.

Dad, you have never failed to answer the phone for a late-night panic call. You have consistently been a level and caring ear when I needed help at work, felt anxious, or wanted to talk any time of the day or night. You supported me throughout this process in every way

imaginable, from bringing over food to reading each of my papers to bragging about me to everyone you met. Thank you for your support, your pride, and your love. I love you.

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Chapter 1

Introduction

The transition into adulthood is a notoriously difficult stage of life for autistic teens and young adults. Autistic teens not only face the ordinary obstacles of their neurotypical peers (e.g. pursuing higher education, navigating friendships and romantic relationships, learning independent life skills), but also may need to manage a transition away from a support system that, for some individuals, has been in place for most of their lives (Ishler et al., 2022). The current study will therefore explore the experiences of autistic young adults as they navigate finding their way from the protected atmosphere of home life and high school into higher education, employment, and the many increased responsibilities and challenges of adulthood. The rationale for the current study is explored through a discussion of the current state of the literature for the various quality of adult life outcome measures discussed for autistic adults and the disparities in quality of life and services for autistic adults with intersectional identities. This literature will then be explored through the context of the outcome measures used to define success in the literature and the shift in research towards inclusion of autistic individuals in the research design and practice.

Very little support is put in place to help autistic high school students transition into adulthood once they leave the K-12 educational system, with over half of adults in a 2017 national report by Drexel Autism Institute receiving no vocational or life skills training after graduating from high school (Roux et al., 2017). It is therefore unsurprising that poor outcomes for autistic adults have been documented across nearly every domain of adult life.

Unstandardized outcome measures across this body of literature create difficulty in pinning down the reality of autistic adult outcomes, a majority of studies find poor to very poor outcomes in independent living, rate of employment, and friendship quality and quantity (Henninger & Taylor, 2013; Mason et al., 2021). However, some research has indicated that these poor outcomes may be more closely tied to characteristics of the individual such as verbal IQ, rather than the presence or absence of an autism diagnosis when measuring adult outcomes (Lord et al., 2020). Additionally, attributes such as higher living skills and happiness were linked with more positive long-term outcomes (McCauley et al., 2020). These studies, while important in understanding how to improve outcomes for autistic adults, have inherent limitations. Many adult autism outcome studies do not include autistic people without intellectual disabilities, a large proportion of the autistic community estimated around 26% (Zimmerman et al., 2018; Hughes et al., 2023). While commonly used categories of adult outcomes such as independent living or employment may not encompass the entirety of ‘success’ as defined by the individual in their own life, they are a jumping off point with which to examine the experiences of autistic adults who transition out of high school into adulthood.

Chapter 2

Literature Review

Employment

Although reports range significantly, a systematic review of employment rates found in various studies report a range of rates from 20-55% for autistic adults (Schwartzman & Corbett, 2022). This persistent lack of employment serves as a major barrier to multiple critical facets of life, including friendships, financial stability, and improved subjective well-being (Solomon,

2020). The disconnect between this population and consistent employment is startling and begs the question of why some autistic adults are detached from the early stages of adulthood.

A review of literature on barriers and facilitators to employment for autistic adults conducted by Harmuth and colleagues (2018) found that autistic adults rarely achieved full time employment compared with their neurotypical peers, and that commonly experienced barriers included poor communication and social skills, exhibiting restrictive and repetitive behaviors at work, sensitivity to sensory stimuli, resistance to change, and poor executive functioning skills. Furthermore, the authors found that mental health issues, in particular depression and anxiety, were a frequently reported barrier to obtaining and maintaining consistent employment for autistic adults.

In addition to factors internal to the individual, Harmuth and colleagues (2018) found numerous environmental barriers to employment, such as lack of long-term workplace support programs, negative attitudes of employers and coworkers, inflexibility in hours, and lack of workplace training. As autistic individuals can benefit from more tailored programs which make use of explicit skills that may be inherently understood as part of workplace culture to neurotypical employees, this lack of training can be an insurmountable barrier to achieving a successful career for autistic adults (Gerhardt et al., 2014).

While much research attention is paid to vocational interventions centering on the autistic individual, an arguably larger barrier to obtaining employment are prejudices held by employers and coworkers about autistic employees (Solomon, 2020). A study by Scott and colleagues (2017) on employers' opinions of autistic adult interviewees found that one in five employers rated autistic candidates as having poor social skills. Although their employment rates are low, autistic adults have strengths that can be enormous assets to a workplace. On average, autistic

adults tend to be more tolerant of repetitive work and demonstrate more dependability and adherence to rules compared with neurotypical employees (Solomon, 2020). However, employers tend to value traits such as self-advocacy and confidence when seeking employment, traits that are difficult for many autistic adults to display in unfamiliar professional settings (Solomon, 2020; Kim, 2014). As a result, autistic candidates face a disadvantage both in the hiring process and in the workplace.

Higher Education

The majority of autistic young adults do not attend higher education, with a 2017 National Autism Indicators Report finding that 36% of autistic young adults attend postsecondary education between high school and their early 20s, a statistic that includes two-year colleges and vocational education (Roux et al., 2017). In the general population, 62% of high school graduates who matriculated within the first nine months of 2021 were found to be enrolled in postsecondary education by October 2021 (National Center for Education Statistics, 2023). The same National Autism Indicators Report found that only 11% of respondents attended a four-year college, compared with 38% in the general population (National Center for Education Statistics, 2023). From those who attend, only an estimated 38.8% of autistic young adults graduate from college, compared to 62.2% for the neurotypical population (Viezel et al., 2020; National Student Clearinghouse Research Center). Furthermore, only one-fifth of autistic young adults from lower-income households attended postsecondary education, compared to over half of those from higher income households (Roux et al., 2017). Given that college is a prerequisite for many high-paying jobs, the dearth of autistic students able to enroll and complete a college degree is a cause for concern when examining factors preventing successful outcomes for autistic adults.

Among those attending college, there are numerous barriers to success. Accommodations are often difficult to receive, as acquiring accommodations often requires paperwork, contact with disability offices, and willingness to disclose one's diagnosis and accommodations to TAs, professors, and college employees (Test et al., 2014; Sarrett, 2018). Autistic young adults often struggle with executive functioning (EF) difficulties, meaning that the coordination of pursuing accommodations, which is often laden with red tape and paperwork, may be additionally challenging. Not all college students feel comfortable disclosing their autistic identity or diagnosis, a requirement for receiving accommodations, with one sample finding that only 69% disclosed during their first several semesters (Gelbar et al., 2015). Roux and colleagues (2017) found that of autistic students who did disclose their identity, only 42% received accommodations. However, even receiving accommodations is fraught with additional challenges. Accommodations in a college setting must be disclosed to each new professor and TA, a challenge of executive functioning, and even once this is done, the accommodations may or may not be honored. Sarrett and colleagues (2018) found that students reported professors only honoring accommodations intermittently, with one participant saying, "accommodations are good if the professor complies. Sometimes the professor does not comply and there is nothing that can be done".

Autistic college students also struggle with mental and physical health issues at a higher rate compared with non-autistic college students, with Jackson and colleagues (2018) finding that half of autistic college students in their sample had a diagnosis of a mental health disorder, and McLeod and colleagues (2021) finding that autistic college students were twice as likely to report worse mental health compared with neurotypical college students. While it is difficult to draw causal links between poor health and declining academic performance, it is notable that

autistic college students report consistently poorer health compared to neurotypical students despite displaying lower rates of behaviors common to college students that could be deleterious to one's health, such as binge drinking and sleep deprivation (McLeod et al., 2021). These poor mental and physical health rates in autistic college students suggest additional burdens in navigating higher education above and beyond the difficulties in EF, obtaining accommodations, and navigating new social environments, as well as the typical demands of postsecondary education.

Intersectional Identities

Non-white autistic individuals tend to be identified less frequently than White individuals, with several studies finding that White students were up to twice as likely to be identified as autistic compared with their non-white counterparts (Travers et al., 2013; Travers & Kerzmien, 2018; Angell et al., 2018). Furthermore, non-white autistic children were less likely to receive a variety of healthcare services, from GI treatment to neurologic and psychiatric care (Broder-Fingert et al., 2013; Smith et al., 2020). A lack of early identification and receipt of needed services has serious implications for development into adulthood, given that early intervention is strongly associated with improved developmental trajectory (James & Smith, 2020). These consequences are illustrated in the poorer outcomes for non-white and low-SES autistic adults, who are less likely to be successful in almost any of the metrics used to measure success in adulthood; postsecondary education, employment, independent living, fulfilling social lives, and service receipt (Eilenberg et al., 2019).

Female and gender-nonconforming individuals are similarly identified much less frequently as autistic in childhood compared with males (Halladay et al., 2015; Tien et al., 2023). This may be due to the role of gender-based behavioral expectations for children, as girls are

theorized to be better at ‘masking’ or covering up unusual or deviant behaviors and are held to lower standards of academic achievement compared with boys the same age (Severence & Howell, 2017). Women are often understudied in autism research as a result, in particular women with intersectional identities such as Black women and girls (Lovelace et al., 2021). Furthermore, autistic and gender diverse or LGBTQ+ individuals experience poorer health outcomes in adulthood, with one study finding that this subpopulation experienced higher rates of mental illness and poor physical health compared with their straight and cisgender counterparts (Hall et al., 2020).

The full consequences of gender and racial/ethnic disparities in identification, support, and service receipt among autistic individuals is not fully understood due to the understudied nature of these intersectional identities. However, these clear inequities in diagnosis and services put this already vulnerable population at increased risk as they navigate the transition into adulthood. These findings demonstrate a critical need to involve a more diverse sample of autistic participants with various intersectional identities in research.

Reconsidering Outcome Measures

The vast majority of research historically conducted on outcomes in autistic adults have found that this community has ‘poor’ or ‘very poor’ outcomes in adulthood, with varying definitions and measurements (Henninger & Taylor, 2013; Magiati et al., 2014). However, measuring outcomes can be difficult, as levels of independence and even individual goals for independence vary greatly amongst individuals. Additionally, the heterogeneity of the autistic community as well as the challenges they may encounter makes prediction of outcomes difficult (Lord et al., 2020). It is important to note that studies examining autistic adult outcomes tend to use outcome criteria that conforms to neurotypical standards of ‘success’. Therefore, these

statistics may not apply to autistic adults with a lower IQ, and these measures can vary between studies (McCauley et al., 2020; Scheeren et al., 2021). For example, Howlin and colleagues (2004) developed a commonly used outcome measure for success in adulthood for autistic individuals called the Overall Outcome Rating (OOR Scale), which is based on categories of independence such as independent living, friendship, and occupational domains. While these goals may be in line with the goals of the individual and their family for their future, many autistic individuals may define success along different axes. Furthermore, only a subset of this research demonstrates high methodological quality (Kirby et al., 2016). Alternative outcome measures have been proposed, such as AUTISTICA (a charity focusing on autism awareness; AUTISTICA, 2016). AUTISTICA suggests that long, happy, and healthy lives should be the primary outcome measures of autistic individuals. However, consistent alternative outcome measures have not been agreed upon and standardized across studies. As a result, a qualitative exploration of autistic adults' perceptions of their own transition into adulthood and what they perceive to be positive and negative experiences and outcomes in their own lives is warranted to gain a greater understanding of where intervention science can focus their efforts in alignment with the community it hopes to serve.

Theoretical Framework

The Social Model of Disability is a framework that examines disability through the lens of societal exclusion and accommodation, examining the way our economic, social, and value structures promote ableism (Oliver, 2013). This model stands in contrast to the Medical Model of Disability, or the idea that disability should be viewed as an often-undesirable deviation from an aspirational standard (often the “average” value of a population on a trait of interest, or the presence of a characteristic that the majority of a population possesses or exhibits).

Related to the Social Model, autism advocates have promoted the concept of Neurodiversity; the idea that neurological differences are part of the natural range of human development (Singer, 2017). The term Neurodiversity encompasses many types of cognitive and behavioral differences occurring naturally in a population but is often used in autism advocacy to promote the idea of autism as a natural state of being to be embraced by society instead of demarcated as a disorder or disability. Advocates of the Neurodiversity movement encourage systems that have traditionally been barriers to neurodivergent individuals succeeding in adulthood to embrace behavioral and cognitive differences and provide increased accommodations to allow everyone to succeed as they are, rather than requiring individuals to change the outward expression of their emotions and perspectives drastically to fit within a Neurotypical world. In order to make these critical changes to the public's perception of autism, the Neurodiversity movement encourages those in academia and other positions of power to listen to the voices of those in the community with the Neurodiversity movement's unofficial slogan: "Nothing about us, without us" (Hoekstra et al., 2018). Autism research in line with the Neurodiversity movement and the Social Model of Disability will therefore be community-partnered, involve autistic participants and collaborators. Additionally, research aligned with these movements will focus on enacting changes to improve quality of life for the autistic individual, including changes to the world around them to meet their needs.

Research centering the autistic individual may also focus on an individual's narrative identity. Interviews with autistic individuals are in large part valuable because they allow researchers to gain an understanding of how autistic individuals conceptualize their own lives and selfhood, an element which has been largely absent in autism research until recent years. The McAdams theory of personality development posits that personality is made up of three distinct

layers: the social actor, representing basic personality traits like agreeableness and conscientiousness which are typically represented by personality tests such as the Big Five, the motivated agent, reflecting the individual's motivations and life goals, and the autobiographical author, representing the narrative identity that we all construct retroactively (McAdams, 2015). This theory has been used in studies that examine life stories constructed by participants as a framework to understand participants' own conceptualizations of their lives (McAdams, 2001). In particular, McAdams theory of personality development cites emerging adulthood as one of the key milestones where the narrative of oneself condenses into a coherent narrative, making this transitional period a useful period to collect data on life experiences (McAdams & Olson, 2010). For the retrospective data examined in this study, McAdams theory of personality development was therefore utilized to understand participants' experiences.

Community Partnered Research

While autistic individuals have not historically participated in autism research in any role except as a participant, recent years have evidenced a shift in thinking within the research community to increasingly center the priorities of the autism community and stakeholders (Roche et al., 2021). Despite this increase in valuing the opinions and priorities of the community, studies that focus on autistic voices remain rare (den Houting et al., 2020). In the rise of the Neurodiversity movement, there is increasing understanding of the value and importance of involving autistic people in research and implementation concerning their community. Community-partnered research also serves as an opportunity to elevate voices not historically prioritized in autism research, such as minority racial and ethnic identities, gender

minorities, and LGBTQ+ participants. These perspectives not only enrich the research community's understanding of the varied and heterogeneous experiences of autistic adults but also provide better context for future intervention development and implementation to a broader array of community members.

Despite this shift to inclusivity, perspectives of autistic teens and young adults are rarely present even in qualitative research centered around transitioning to adulthood compared with other perspectives such as parents, therapists, counselors, and community stakeholders. In a review of qualitative studies surrounding the transition to adulthood in autistic young adults, Anderson and colleagues (2017) identified 17 studies between 2000 and 2015 meeting their criteria, only two of which focused exclusively on the voices of autistic youth. In the last several years, more qualitative research has been conducted centering the voices of autistic individuals, although they are often positioned alongside other perspectives on the transition to adulthood (e.g. Steinberg et al. 2023; Lee et al., 2022; Lee et al., 2023). Of existing research that does solely center autistic voices, many such studies limit their participants to those attending college or higher education (e.g., Davis et al., 2021; Kim & Crowley, 2021; Fabri et al., 2022). There is a call for research elevating autistic voices that is inclusive of a broad array of post high school transition lived experiences.

The Current Study

Given the poorer outcomes in adulthood for autistic individuals across nearly every metric, there is a critical need for research examining the transition to adulthood for autistic youth. Furthermore, there is a call for research centering autistic individuals and their experiences (Benevides et al., 2020). Therefore, the current study focuses on the experiences of autistic adults transitioning out of high school and into adulthood, with the hope of

understanding some of the invisible barriers preventing success along commonly used metrics such as employment, independent life, and social outcomes, as well as gaining a greater understanding of how autistic individuals assess their own happiness and quality of life. The goal of this study is to shed light on the experiences of these individuals, what was helpful in promoting positive outcomes in adulthood, and what hindrances they have experienced in their transition.

Research Questions:

1. What are the barriers autistic individuals encounter in the transition to adult life?
 - a. What barriers did autistic individuals experience in higher education?
 - b. What barriers did autistic individuals experience in employment?
2. What resources do autistic individuals find most helpful in navigating this transition?
3. What could families, organizations, employers, and educators do to support autistic adults transitioning into adulthood?
4. What strategies for success do participants recommend to autistic emerging youth to navigate the transition into adulthood?
5. What does success mean to autistic individuals in their own lives?

Author's Positionality

I am not autistic. I am a family member of an autistic person. I have worked for many years in the autism community in various settings as a teacher, behavioral aide, researcher, and co-creator. While most participants were unknown to me prior to the study, several of the participants interviewed had a personal connection with me, as I worked for several years at an

organization where these individuals took classes. I took steps to mitigate potential pressures or biases that might occur from this connection (described in participants section of the methods) but believe that this prior connection improved the interviews through trust and familiarity with the life experiences of these participants, as well as their increased comfort levels with me.

Two autistic collaborators were involved in the creation of this manuscript. One collaborator worked on thematic analysis, framing, and editorial feedback, while the other acted as a sensitivity reader and provided editorial feedback.

Chapter 3

Methods

Participants

Eighteen autistic adults (ages 18 and over) were interviewed. This age range was selected to capture the lifelong perspective of post-transition to adulthood, seeking the viewpoints of both those who are undergoing the transition as well as the retrospective viewpoints of those who were settled into adulthood. Furthermore, the age range was deliberately kept broad as, throughout the interviews, it became evident that for many of the participants, the trajectory to achieving ‘adult’ success (e.g. employment, independent living, etc.) took until their mid-thirties and was non-linear. The study team received the feedback that including a broader age range would be considered neuro-affirming as it would include those whose transition trajectories took a different path from the typical standard. For the purposes of this project, participants over the age of 40 were excluded from analysis, leaving a total of 17 participants included in the final analysis. This choice was made due to the desire to focus on the experiences of young adults in the current state of the job market, educational system, and social environment. Participants were

recruited primarily through social media, and secondarily through an organization that specializes in facilitating careers in the entertainment industry for autistic teens and adults. When recruiting through this organization, all recruitment emails were sent through the organization to ensure that participants felt comfortable declining or asking questions about the project that they might not be comfortable asking the primary investigator. Convenience sampling was employed for participant recruitment, as I utilized prior employment history with the organization and was therefore known to many of the participants prior to the study. Social media recruitment was conducted through Instagram by creating an autism research account and posting IRB-approved fliers to the account.

Initial recruitment was conducted via email. If participants were interested in learning more and potentially engaging with the study, they were instructed to make initial contact with the study email address to learn more. Those who indicated their interest were then provided with the consent form to review, along with a Google Survey to determine their eligibility by asking if participants were autistic adults aged 18 or over. The survey also collected demographic information from eligible participants, such as their primary language, age, ethnicity, type of high school attended, and presence or absence of an autism diagnosis or self-identification as autistic. Participants were considered eligible if they identified as autistic adults and were ages 18 or over. Full participant demographic information can be found in **Table 1**.

Table 1. *Participant Pseudonyms and Characteristics*

| Participant ID | Pseudonym | Gender | Age | High School Type | Racial/Ethnic Identity | Primary Spoken Language | Diagnosis |
|----------------|-----------|-----------|-----|------------------|------------------------|-------------------------|-----------|
| P_01 | Jamie | Nonbinary | 26 | Mainstream | Mexican-'American | English | Autism |
| P_02 | Arlo | Male | 28 | Mainstream | White/Latino | English | Autism |
| P_03 | Ben | Male | 31 | Mainstream | White | English | Autism |

| | | | | | | | |
|------|-----------|-----------|----|--|--|--------------------------------|-----------------------------------|
| P_04 | Kayden | Male | 28 | Mainstream | White | English | Autism |
| P_05 | Kiki | Female | 19 | Mainstream and Special Education | White | English | Autism |
| P_06 | Alex | Nonbinary | 23 | Special Education | White | English | Autism |
| P_07 | Kyle | Male | 22 | Mainstream | Hispanic/Latino and White, Multiracial | English, French, Spanish | Autism |
| P_08 | Jane | Female | 35 | Mainstream | Middle eastern/Caucasian | English | Autism |
| P_09 | Zach | Male | 32 | Mainstream | White | English | Autism |
| P_10 | Sam | Nonbinary | 28 | Mainstream | Indigenous Native American | English | Autism |
| P_11 | Rose | Female | 22 | Mainstream | White | English | Autism |
| P_12 | Sarah | Female | 36 | Mainstream | White | English | Autism |
| P_13 | Katherine | Female | 24 | Mainstream | White, Non'- 'Hispanic | English | Autism |
| P_14 | Rebecca | Female | 25 | Mainstream | Hispanic | English | Autism |
| P_15 | Nina | Female | 25 | Mainstream | White | English | Autism |
| P_16 | Maddie | Female | 22 | Mainstream | biracial (black and white) | English | Self- 'identify as autistic |
| P_17 | Emily | Female | 29 | Mainstream | Hispanic/White | English | Autism |

Materials

Interview questions as well as a demographic Google Survey were used for this study. Interview questions can be found in **Figure 1**. Zoom was used to record interviews and create initial transcriptions which were then subsequently edited by the study team. Google Survey was also used to send follow-up surveys via emails to participants.

Procedures

Development of Interview Protocol

The interview protocol was designed to ascertain the quality of various domains of the participant's life at the time of interview including independent living, education, vocational

skills, and social skills, to investigate the life skills preparation in these domains the participant did or did not receive, and to ascertain what the participants considered to be the most helpful and detrimental aspects of those transition experiences. Additionally, the questions addressed potential additional support that participants might have found helpful in their transitions into adulthood. The questions were designed to be open-ended, and the semi-structured nature of the interviews allowed for conversation to evolve naturally and for participants to center their most salient experiences.

Interviews

Interviews were conducted virtually through the Zoom platform which allowed for face-to-face conversation with participants from their own home. The primary investigator took calls from private rooms with headphones to assure data security and participant privacy. These sessions were recorded using Zoom's recording feature to ensure accuracy in data capture. The Zoom-generated transcripts of the interviews were subsequently anonymized, carefully reviewed, and edited to ensure accuracy, as Zoom's automatic transcription feature did not consistently capture transcriptions correctly. The purpose of this editing process was to rectify any inaccuracies or omissions in the transcripts, thereby preserving the fidelity of the participants' responses and maintaining the integrity of the data analysis.

Participant Rights and Consent

Before recording began, participants were provided with the study's protocols and their rights as participants. Prior to filling out the eligibility form, participants were asked to review the consent form and ask any questions they had before being interviewed. Time was made during each interview before recording began to address any questions or concerns participants

had about the interview, review the consent form, and to explain the purpose of the study. Participants were also asked about their comfort level with being recorded, and verbal consent was obtained before proceeding with the interview. Each participant was told that they could stop the interview at any time, take breaks, or turn off their cameras if they felt overwhelmed or uncomfortable. Participants were given the right to withdraw their interview or edit their transcripts at any time. Member checking was conducted to ensure that participants felt their voices were accurately represented and give them a chance to change, withdraw, or add to their quotes. Participant information and pseudonyms can be found in **Table 1**. This study was approved by the University of California, Los Angeles North Campus General Institutional Review Board.

Post-Interview Survey

Following the completion of the interviews, participants were sent a follow-up email expressing gratitude for their participation. They were also invited to complete an optional post-interview survey, providing an opportunity for them to share additional feedback on their interview experience and their overall level of satisfaction.

Data Security

Recordings and transcripts of the interviews were stored on a secure, password-protected online server. Access to this server was restricted to research staff who had been approved by the IRB. Transcripts were de-identified by the research team prior to data analysis. Pseudonyms were assigned for all participants.

Data Analysis

Data analyses followed the guidelines for reflexive thematic analysis proposed by Braun and Clarke (2006). An iterative and inductive approach was employed to code the data and

identify recurring themes. The analysis involved multiple read-throughs of each transcript, during which I noted recurring sentiments and emerging ideas. Any ideas that arose in more than one transcript were written down, and a tally was kept of how many transcripts mentioned this burgeoning theme, as well as how often it was mentioned. Once the transcripts had been read through multiple times and this process had been repeated to ensure no themes had been missed, the themes were ordered by frequency. Themes that appeared in three or more transcripts were kept, as well as themes that appeared more than once in two or more transcripts to ensure the capturing of the most salient themes to each participant's interview. Once this step was complete, I organized the identified themes into a codebook, a dynamic document that is designed to evolve throughout the coding process. The codebook contained the theme, a description of the theme, and several example quotes that would be illustrative of each particular theme. Once this was completed, the software Dedoose (Dedoose Version 9.0.23) was utilized to facilitate the analysis of the data. I revisited the seventeen anonymized transcripts for a second round of coding, during which adjustments, refinements, and deletions were made to the codebook as needed. All transcripts were uploaded into Dedoose as well as the codebook, where I completed first a preliminary round of coding using the existing codebook. Once this first round was completed, I reevaluated the codebook, condensing themes if there was a great deal of overlap or similar definitions, and separating out themes from overcrowded or heterogeneous collections of quotes under certain themes. After the needed refinements to the codebook were made, I coded all the transcripts a second time and repeated this process. Finally, I reviewed the transcripts a third time to ensure that I had not missed any emerging themes or that my perception of my own codes had not changed with familiarity with the text. Once this was completed, I moved on to ascertaining interrater reliability.

Interrater Reliability

A systematic coding consensus approach, following the framework proposed by Willms and colleagues (1990), was then employed. I met with a research assistant to code a subset of the transcripts separately, and subsequent discussions were held to reach consensus on any discrepancies. This iterative process allowed the coders to construct a robust coding system and achieve agreement between raters. This iterative process allowed the coders to construct a robust coding system and achieve agreement between raters (Richards et al., 2018). Coding and consensus procedures continued until the reliability coder and the master coder reached an agreement of over 80% (Syed & Nelson, 2015). This threshold was chosen to ensure a high level of consistency and reliability in the interpretation of the data. For frequency of codes applied to each major and subtheme, please refer to **Table 2**.

Chapter 4

Results

Data analysis yielded several overarching themes: Educational/Vocational Experiences after graduation, Barriers to Success, What Worked to promote success in this life stage, and Recommendations to various people and institutions that could promote better outcomes in future generations of transition-aged youth. Each of the major themes contained subthemes.

Educational and Vocational Experiences

Accommodation and Special Service Experiences: College/Higher Education

In college, participants had mixed experiences of accommodations and service experiences. Some reported their services being promptly fulfilled and everything flowing smoothly, although this was uncommon. Emily, who attended a mainstream high school and is

currently attending college to become a therapeutic theater teacher for neurodivergent children and teens, explained that her experience communicating with the disability center at her college was fruitful: “I made the effort to get with the disability center and make sure I gave them all of my paperwork and requested my accommodations early and all of that...all of those are being fulfilled.”

Emily attributed a large part of her success in college to her accommodations, as well as her ability to advocate for her needs. Maddie, who attended community college, has worked several entry level service jobs, and writes fantasy novels, described a similarly positive experience with her community college, saying, “I think they did a really, really good job. They were very accommodating.” Rebecca, a community college student studying environmental science with a focus on sustainability, likewise expressed being met with supportive disability services employees: “It was actually a lot easier than I thought to get the accommodations... I thought it was going to be like, this whole long process of fighting for accommodations... [But] they were super nice. They just went over the accommodations they can offer and... signed me up for all of them.” Rebecca also explained that the most helpful accommodations she received were notetakers in-class, as well as flexibility with attendance and time on exams:

“I plan on maybe utilizing my notetaker accommodation so that I can have somebody that can take notes for me because I have a hard time taking notes and listening and observing the information at the same time, so I think that would be helpful. Being able to get up and leave class when and as much times as I need to...The main [accommodation] I’ve been using was... extra time on tests.” (Rebecca)

While several participants reported positive experiences with accommodations, many more participants discussed their negative experiences trying to navigate disability offices at their universities. Rebecca describes her experience navigating the disability services office in the effort to obtain necessary accommodations:

“The process of some of the accommodations... is a lot of steps and it’s daunting, especially for somebody with ADHD. Because it’s like, oh, you know, you gotta let your professor know ahead of time. You gotta fill [those forms] out. You gotta go and pick up the paper and fill it out and you have to do it by this amount of time and you gotta do blah blah blah. And I’m like, that’s a lot just to be able to take my test somewhere else... I feel like there needs to be a better process for that, because I...already have ADHD and struggle to do my own little tasks and chores at home. I don’t want to have to do all those steps and I might not remember to do them within that timeframe. So I feel like there’s still barriers even when you have accommodations.” (Rebecca)

Rebecca was far from the only one who expressed that the process of obtaining accommodations was at times so daunting as to deter service receipt. Participants described navigating disability services offices as an obstacle course of executive functioning skills, requiring all the skills that were most difficult for them. For some participants, the work of obtaining accommodations was a strong deterrent from pursuing higher education. For Rose, who now works with children on the spectrum as a behavioral aide but who withdrew from college during the pandemic, her experience with a disability services officer was pivotal in her choice not to return to finish her degree:

“The academic advisor, I went in to get accommodations, and talk about it when I was just barely newly diagnosed... And she went, okay, well, what accommodation do you want? And I was like, I thought that’s what you were going to tell me. I didn’t know I was supposed to come in with a list, like do you have a list? I can circle the ones I want. And she was like, no, you’re just supposed to tell me... And so it wasn’t helpful and it made me kinda even more worried about going back. Because if even the... accommodation officer for the school doesn’t really understand, why would I be able to count on the teachers and professors?” (Rose)

Rose’s poignant statement illustrates the impossible position many autistic and neurodivergent students are forced to navigate. If an autistic student needs accommodations, it is likely due to the fact that they need support in executive functioning and other daily life tasks surrounding academia.

Obtaining an autism diagnosis in adulthood is notoriously difficult and costly (Huang et al., 2020). Support services for autistic adults are inconsistent, and there are a multitude of reasons ranging from time or financial constraints to cultural considerations that dictate whether or not an individual may pursue an official diagnosis (Thomas et al., 2012). However, college disability offices may require medical documentation of a disability or condition in order to provide paperwork for accommodations, leaving many undiagnosed students unable to pursue necessary services. Kyle, who struggled during college but now is attending graduate school, explained:

“They want you to provide paperwork as to why you need... accommodations... Usually a lot of the time, it requires you to have a diagnosis, and so maybe sometimes, these people might not have a diagnosis or self-diagnosis might not necessarily be accepted.”

(Kyle)

Finally, lack of self-knowledge and self-acceptance played a role in participants' decisions about accommodations in college. Nina, who graduated college and now works full time with neurodivergent children with behavioral needs, explains that “in college, I really hid it because it felt like people don't want to be friends with someone that's autistic... Now I'm very open with it, [but] I didn't ask for accommodations at all.” Similarly, Sarah, an educator who works in the social service side of intervention after realizing she was autistic and going through burnout in her job, explains that her lack of knowledge about her own autistic identity at the time prevented her from pursuing services: “Looking back, it definitely would have been helpful. Since I didn't know this about myself, I did not use any accommodation.” For some, however, this state of being able to ‘get by’ without accommodations would not last.

“I was able to mask so well... I could blend in like a neurotypical person. But then coming to grad school and being more accepting of my autism and learning more about it, I'm realizing, I need some... accommodations, because it's difficult... So I guess that's the transition I will have to figure out in grad school, whether or not I need some academic accommodations.” (Kyle)

Accommodations are an integral part of many autistic students' experiences with college. The difficulty in navigating disability services offices, resistance from professors and staff, and stigma surrounding service receipt placed additional and unnecessary burdens on autistic students in this sample, adding to an already difficult time of transition. As Jane, a nurse and mother of neurodivergent children, said of her experience in college attempting to navigate the system of accommodations: "I just feel like the world is not a very compassionate place to begin with, and if you're different, it's even worse."

Accommodation and Special Service Experiences: Employment

While most participants discussed their experiences with accommodations in the context of college or higher education, several shared experiences of pursuing accommodations in a work environment. Nina, who works in a company that is supposedly welcoming to neurodivergent employees, shared that she feels as though the support the company provides is more for the optics of the company than to support their neurodivergent employees: "The new company I was working with... there's an autism advocate group that [friend] and I are a part of... They really helped and they understood that... They made [friend] work nine hour days and that's really bad... they forget his condition, like they say they're supportive but they're not." (Nina).

Many workplace accommodations that companies and organizations can provide for their autistic employees are relatively easy to execute. A scoping review of workplace accommodations for autistic adults recommended minimizing distractions, reducing noise, and ensuring predictability in daily tasks, as well as providing job coaching (Khalifa et al., 2020). However, these relatively simple adjustments as well as other accommodations the workplace might provide for its autistic employees require employers to listen carefully to the needs of their

employees. As Nina explained, her primary request for her company was to “[Listen] to my needs, like what kind of clients I needed because... I even get overstimulated if the kids [are] going wild. Okay, they’re not listening to me... I’m going to get burnt out.” (Nina)

While many autistic employees are loath to ask for accommodations, many participants ultimately discovered that they were unable to get by for extended periods of time without them. The strain of masking for years on end and attempting to keep up with the demands of a neurotypical workplace took a toll. As Kyle explained, “I’m realizing, crap, I need some accommodations because...It’s difficult when the world isn’t designed for us.”

Routines/Change

The importance of routines and resistance to change is well cataloged, both in the experiences of autistic individuals and in research (Mirzaie et al., 2018; Petrolini et al., 2023). Many coping techniques and therapies for autism rely on establishing palatable daily routines to help with executive functioning difficulties as well as minimizing anxiety for the individual due to foreknowledge of the day’s events (Rutherford et al., 2020; Stark et al., 2021). It is therefore unsurprising that major life changes such as moving away from home, going to college, transitioning out of high school, or getting a job might cause anxiety and other difficulties for autistic individuals as routines shift and unexpected experiences arise. As Arlo spoke about moving out of his family home and in with his girlfriend, he described his struggle adjusting to the new environment: “Generally, it’s very difficult... to adjust to new areas, even if it’s just the same city... I do try to be open, which is another thing that is often not very easy to do as someone on the spectrum.” However, he found peace with this change, remarking that “with change, you’re not going to lose everything...you may lose your apartment and you go to a new one, but you didn’t lose yourself.” Zach, a writer, autism advocate, and public speaker, had a

similarly difficult transition at the beginning of his college experience, but found that over time the shift became easier to tolerate:

“Academically, it is still a bit of a struggle. And with the masking I do constantly, it’s definitely draining. But as I look back, the transition gets easier after maybe the first two or three semesters, because it’s almost like a new routine. When there’s a new routine, it gets really difficult to get into the swing of things. But after that routine starts happening, then it starts to get easier.” (Zach)

While some participants found their new routines difficult but tolerable, others found that the shift in daily routines were overwhelming to the point that it became unmanageable. In particular, the lack of structure in college compared to living at home and attending high school was overwhelming for Rose: “Not having a designated time set aside to do homework... was really difficult... going through college, you’re kind of responsible for making that time. And that did not happen, and it did not go well.”

Rose is by no means alone in her experience, with many qualitative accounts of autistic college students expressing a wish for more guidance with an advisor or counselor, expressing a wish to participate in academic coaching, transition programming, and tutoring (Wolpe, 2024). Participants who received support from family and counseling reported that it made a difference in guiding them through their college experiences: “When I had that family support and I did go to counseling... that was really supportive, and so that kind of helped me steer to the path of... the psychology major I want” (Nina).

Despite the stress of changing routines, some participants expressed that they enjoyed the increased flexibility of jobs or college schedules compared to the rigidity of their high school days. Jamie explained that college allowed them to “create my own structure, my own schedule...I was able to figure out what works best for me. I have more flexibility... so I think that worked really well for me” (Jamie). While the difficulty of transitioning out of a safe routine could disrupt participants’ sense of stability and sense of control over their lives, the ability to shape their own routines to fit their personalities, interests, and sensibilities was seen as an advantage after a lifetime of routines and schedules created by other people and imposed upon them.

Masking

Masking, or the act of camouflaging parts of oneself or suppressing behaviors around others with the goal of conformity or social acceptance, was a frequent subject of discussion among participants. Autistic young adults reported engaging in masking behavior for a variety of scenarios and motivations, but most often, in the workplace. Emily discussed engaging in masking behaviors to improve her social relationships as a child, and to try to keep her job as an adult. Other participants reported similar masking behaviors at work, with several describing the difficulty of keeping up a high level of masking in a professional environment: “I had to be very careful that I’m not stimming with my hands... or if I do it, it will be hidden...under the desk... making sure I’m able to be professional.” (Jamie). The difficulty of not only exerting typical effort to curtail their natural behaviors in a professional environment, but additionally controlling natural movements and self-soothing behaviors in an anxious situation can prove too much for

many autistic adults, who find themselves in a position of being unable to maintain masking for very long:

“When you have a job, especially in customer service, you have to present yourself in a certain way...I worked really hard to come off as confident and talkative but my memory is not that great. So having to do my job on top of masking was really difficult. And I couldn’t keep it up a lot of times, so I would lose jobs because I wasn’t able to keep it going for very long.” (Sam)

Even for those who were able to keep up the constant facade, it could be draining and costly in other areas of their lives: “I felt like I was always pretending non-stop and it was exhausting” (Jamie). While many felt that masking was a necessity for maintaining jobs and professional relationships, the cost was high, and it was not always effective for succeeding in adulthood.

Masking was not just explained as a behavior developed to fit in when attempting to exist in a professional setting. Many autistic adults explained that they learned masking at a young age to please their teachers, family members, or to fit in with other children. Sam explained that they learned masking as a child to please their parents and avoid shame, embarrassment, or punishment:

“My family’s Mexican...I grew up not knowing the most about mental health... it’s not something that was talked about or really understood. We had to do well in school, that

was our responsibility. And so when I started to struggle... I knew if I was struggling I wasn't going to get help. I was going to get reprimanded... or hit." (Sam)

Similar to Sam, many participants reported learning masking in childhood to gain social acceptance and praise from adults and to avoid ridicule from other children. However, this could be a conundrum for those able to mask well enough that they were not perceived to need any special services. One participant recalls, "I was in special education, but I guess I got out of special education because I was able to mask" (Kyle). Zach, a young man who has been successful in navigating the job market, describes his intense ambivalence with masking:

"Masking is a double edged sword...the masking I've had to do to transition into adulthood... felt like being a chameleon of my true self. I would be accepted more in society and accepted more by other peers and teachers that I was comfortable with... I still haven't decided if I want to unmask and be my true self because I don't know how my peers, coworkers, teachers, etc. would react. It's like a shield in a way... helping me get through college, life, adulthood, and so on." (Zach)

Autistic adults described over and over the toll that masking took on their mental health, energy levels, and relationships with others. Other participants recalled positive experiences with unmasking, or the process of lowering the inhibitions and constant self-monitoring to prevent certain socially unacceptable behaviors or movements from occurring in a social situation. Despite participants' original intention of masking as an avenue to social acceptance, many autistic adults realized upon unmasking that their social lives eased with the introduction of their

authentic ways of relating to others: “I was like, okay, maybe I am autistic... after I made peace with that and started living not as somebody who was...trying to constantly mask... as soon as I communicated with my friends and my support group... everything became significantly easier to deal with” (Maddie).

While some autistic adults found peace in learning to unmask, others struggled to dismantle the systems of protection they built throughout their childhood. Rose explains, “It’s been a huge disadvantage... learning to mask so well that you kind of forget who you are in the transition to adulthood. I thought I was supposed to be this and now I don’t fit in that, and I don’t actually think I ever did. But now, I can’t even act like I do. So then you’re left like, where do I go now? What do I do?” (Rose).

Ultimately, the message these participants received from their schools, their jobs, their friends, and even their own families, was that their true selves were unacceptable in many or all circumstances, and that they should work as hard as possible to fit in regardless of the cost. As Jamie explains, “I [had to] pretend that I’m normal... I had to speak in a certain way that wasn’t me.”

Friendships/Relationships

Autistic individuals often struggle with creating and maintaining friendships, with fears of abandonment and experiencing uncertainty in how to respond to social interactions commonly reported by autistic research participants (Black et al., 2024). However, the participants all reported a strong desire for friends, and for community. Jane explained, “I think autistic people, they get labeled as anti-social and they don’t interact and they’re not friendly and they can’t make friends. But I think the reality is we do want friends. We just don’t know how to do it sometimes. Gradually easing into those social situations so you don’t get overwhelmed... finding

situations where you feel more comfortable so it's not as intimidating or there's not as many expectations." While participants reported the desire for friends, actually creating those friendships was more difficult. Those who found friends explained that they relied on their friends to be understanding of the different ways they might have to socialize or the challenges that came with social events: "My social skills are not as developed as my friends are, so I kinda depend on them to do a lot of the heavy lifting as far as, you know, being social. But so far it's been okay, and they've been very patient with me. And it's been awesome how patient they've been with me" (Maddie).

Participants reported being frequently identified by neurotypical peers as autistic, or at least as 'different', at a young age. Jamie recalls, "Kids knew that I was neurodivergent before teachers or adults did, I got made fun of... My nickname was Aspie. Which, I didn't know what that meant." Elementary and middle school were unsurprisingly difficult times to socialize. Sam recalls drawing inward and feeling uncomfortable making friends during this time period because of insecurity surrounding school performance: "The fact that I was not really understanding a lot of what was being taught to me in school or socially caused me to maybe have less confidence in myself. So I...[became] quieter and more introverted" (Sam).

After high school, while the social landscape changed, participants continued to struggle to build friendships. Jane described her struggle to integrate into social situations and make friendships as integral to her experience of her emerging adulthood:

"I have never understood a lot of the social aspect, and I think a huge part of the transition to adulthood and college... is that social development and understanding those unwritten rules that are everywhere and kind of govern all your interactions, even if you don't realize it." (Jane)

Participants echoed the sentiment that they were constantly running into social barriers in making and maintaining friendships through missing social cues, or violating social norms without meaning to do so or due to things they could not control. As children grow into teenagers and young adults, the expectations for their public behavior become more rigid and specific, leaving many autistic young adults further outside the socially acceptable sphere of adult behavior. Maddie explains that she often finds herself acting in such a way that violates expectations for her age and gender, and has difficulty explaining her behavior in such a way that satisfies the understanding of the people around her:

“A lot of the things I do, a lot of the things that I feel, the way that I think, a lot of it is not perceived by other adults as being adult behavior... A good example of this is that I get overstimulated very easily. Me and my friends like to go to the mall and sometimes, you know, malls can be very crowded. And just sometimes the crowd, the sounds, you know, people’s feet shuffling, there’s so many people. It feels like I’m in a very small room that’s getting smaller, smaller, and smaller. And so because of that, I need something to ground me and usually that’s something that I can do with my hands, or I don’t ever leave my house without my airpods in, so that I can listen to something to block everything else out... When I do those things, you know, when I kind of stop talking because... talking just takes too much energy when I’m overstimulated, when I’m playing with a fidget toy or something. People look at that and they don’t think, oh, this is somebody with a disability or this is someone who has autism. They think, what is wrong with that person?” (Maddie)

Maddie's behavior is not intended to violate social norms, but rather, to make social activities such as going to the mall with her friends tolerable for her. For Maddie to maintain her friendships and participate in social activities, she needed her AirPods to prevent overstimulation, and to play with fidget toys to handle overwhelm. However, these activities are not considered socially acceptable, leading to an impossible position. Maddie, whose friends are supportive of her and understand why she might have to step out of a crowded store, still runs into struggles with her own family as to why she has to do these seemingly 'odd' activities:

“Trying to explain to a lot of the people in my life... look, I'm not doing this because... I want to play with the [fidget] toy... A lot of times I will have someone being like, why are you playing with a toy, you're 22 years old, that's kind of weird, isn't it... and it's like, how do you explain that to somebody? I'm overstimulated... and they're like, why? That's so weird, like what do you mean, overstimulated? And it's just, trying to function as an adult when everything that you do in that moment is perceived as childish behavior. Trying to explain and articulate to people why I do what I do or why I think the way I think, why I need somebody to go into the McDonalds with me to ask for sauce because I'm terrified, you know, of having that interaction with someone I don't know. It's really difficult to explain that in a world that doesn't want you to give you an excuse for anything.” (Maddie)

Several participants echoed Maddie's experience of being questioned about their behaviors and having to explain that they were not just being childish or intentionally inappropriate. Jamie explained their experience with their mother and friends, who questioned why they only spoke in movie references:

“I remember my mom being like, ‘why do you just talk about movies?’ Or even like classmates in college have been, ‘are movies the only thing you talk about?’ And I’m like, um, okay. ‘Cause for a long time I was nonverbal, except when it came to movies or shows. That’s the only way I can communicate....My friends are like, you should know this. I was like, no, I never got taught that. I had to learn through movies and shows, you know, which is not the best way to learn about social communication skills.” (Jamie)

Jamie has become more successful in adulthood in making friendships, describing themselves as extraverted and friendly, but has more trouble making lasting friendships due to the natural behaviors that come out as they begin to relax and become more comfortable with a new person:

“I’m good at making those connections and getting to know them and being friendly, but having long-lasting friendship is a lot more harder because the more people got to know me, the more comfortable I got. And the more comfortable I got... I started un-masking more. I started being more comfortable to have a meltdown, or... act more weird and talk more about Star Wars for like, all day... but even then it was so hard... I felt like I was always pretending nonstop and it was exhausting.” (Jamie)

Participants explained that, even when they were able to make friendships, maintaining those relationships was often difficult due to the increased expectations of a closer friend, or due to the difficulty in understanding the nuances of relationships. Several participants spoke to the added obstacle of navigating more complex relationships, either unhealthy friendships or even romantic relationships. Boundaries that might feel intuitive must be learned explicitly for autistic

young adults, and identifying people with malicious intent is additionally challenging for people who miss social subtext.

“It’s more the social emotional relationship piece, not just with peers and friends, but, romantically and sexually. I think that’s a whole other issue that doesn’t really get talked about very much, like navigating dating and romantic relationships, and appropriate boundaries. And kind of recognizing when something is unhealthy or abusive... I think autistic people are more susceptible to relationships that are abusive or take advantage of them, because we don’t necessarily have all the same social and emotional tools that someone else might have, and we might not recognize something as abusive.” (Jane)

Autistic individuals are at increased risk for romantic or sexual abuse, and are less likely to confide in others about their experiences compared with neurotypical peers (Roberts et al., 2015). There are many theories for why this might be the case, among them difficulty understanding others intentions, increased desire for social acceptance, and a lack of awareness of social rules leading to the inability to identify dangerous or abusive behaviors in others (Gibbs et al., 2021). Jane describes the experience of trying to handle conflict for an autistic individual:

“One of the challenging things... is that when you encounter... conflict, it’s really hard to know what to do in the moment, and if you struggle with alexithymia and you get upset and you freeze... and then later, it all comes flooding in. It’s really hard to know how to manage those situations, you know, especially socially, it’s really difficult and boundaries are difficult. And all these social rules are piled on top of that.” (Jane)

Alexithymia, or the difficulty in describing emotions, is common in autistic individuals and can make navigating tense or dangerous social situations additionally difficult because the individual may not be able to identify their own response to the situation (Kinnaird et al., 2019). Without this internal compass, pinpointing behavior that makes the person uncomfortable or upset becomes more difficult and therefore leaves the autistic person open to additional mistreatment and, in some cases, abuse.

While many participants reported having wonderful, strong friendships, friendship was a frequently discussed topic and one that evoked many upsetting and sometimes traumatic recollections for participants. A deep aspect of their experiences surrounded fundamental feelings of rejection and isolation, leading to deeply conflicting feelings of wanting friendship and connection while at the same time fearing a poor outcome of putting themselves in a vulnerable position to achieve this goal.

Barriers to Success

Timing of Diagnosis/Gender Differences

Timing of diagnosis was a key theme in understanding participants' experiences. Participants who reported being diagnosed after age 18 were all women and one nonbinary individual, with another nonbinary participant and one male participant reporting being diagnosed as children but only learning of their diagnoses in adulthood. Autistic women are more likely to be diagnosed in adulthood compared with autistic males (Leedham et al., 2020; Huang et al., 2020), while research on typical age for nonbinary and gender nonconforming autistic individuals to receive a diagnosis remains sparse. One participant discussed how, even

though she had younger brothers who received an autism diagnosis during childhood and in retrospect, she displayed similar behaviors and challenges, nobody in her family suspected she might be on the spectrum:

“If there had been more research... that would have been, I feel like, very beneficial in just not feeling... I guess, defective throughout... middle school and high school and then into adulthood, like, oh, I’ll eventually grow out of it ‘cause that’s what my mom and sisters said, she’ll grow out of it, right? No, it’s not something you grow out of... If that had been understood, I think that the connection would have been made earlier for me specifically and not until I had to do the work to figure it out on my own in the middle of my twenties.” (Emily)

Emily’s late in life diagnosis caused her to struggle immensely during high school and beyond, not knowing why she was so challenged by things that had proved simple for her older sisters. Even when her brothers were diagnosed with autism, she still did not recognize those characteristics in herself, in part due to the strong stereotypes of male autistic behavior. Emily recalls, “I didn’t think that I was autistic, especially because a lot of the research and symptoms that I was looking up to help with my brothers were researched with boys... I would be like, oh, yeah, I do that. But then I thought that just might be a quirk that runs in my family... But if that had been looked into, it would have saved us so much trouble and so much heartache and so much pain.” Emily’s regret over a late diagnosis was not just due to the emotional turmoil it caused her and her family to not understand her—she also reflected on how school would have been much more manageable if she had received a correct diagnosis.

“My brothers are still in the same school system, they do [assess] that now... I don’t know why the effort wasn’t put in for me...I think about finishing high school if I was medicated correctly. I’m like, I would have done so well, I would have been able to complete things...[if I had] had help in classes, like an IEP or something like that. That would have been very beneficial. But no, none of that happened.” (Emily)

Emily, who spent her high school years being misdiagnosed and put on heavy antipsychotic medication that caused her extreme drowsiness and other symptoms, did not receive much support at the hands of the school system as a result. An earlier diagnosis, she expressed, would have made all the difference in her life trajectory.

“I was misdiagnosed with bipolar and was put on a really high dose of Abilify... I don’t remember much of my senior year. I just remember falling asleep a lot in class and my grades slipping so much that my teachers were very concerned because I was an A, B average student...they were like...all you have to do is just try to get through because right now we don’t see you graduating. We don’t think that you’re gonna be able to do anything. And I was just so disheartened... I am not usually like this, and yet here I am, at a very low point, and I’m essentially being told that, there’s no future for you. And it was really sad.” (Emily)

Emily expressed a deep despair, a thorough experience of demoralization, saying, “Not only was I isolated by...school, staff, school friends, but... I ended up isolating myself, because I was just like, there’s no point in even trying anymore.” This devastating experience, in Emily’s view, could have been avoided with a correct and timely autism diagnosis. While Emily is now thriving and working towards establishing her own therapeutic theater practice where she can

incorporate her love of performing arts with her desire to help neurodivergent youth find their passion, she has not forgotten her experience in high school, and is a fervent advocate for timely diagnoses for neurodivergent youth.

Emily is far from alone in her experiences. Maddie shared her experiences in recontextualizing her life experiences now that she has received a diagnosis and has come to terms with her autistic identity:

“When I was a kid, it’s not like I didn’t have autism. I’ve had autism my whole life. I just didn’t know it. So when I found that out and when I finally made peace with that and recognized it, it explained a lot of things that I thought made me very alien... When I was little, the sound of fireworks were terrifying for me... When I was in high school... kids can be cruel... they made fun of [me] for my, you know, “odd behavior”. The fact that I can’t make eye contact with people for more than a few seconds. The fact that I seem to ramble on, you know... now that I have this diagnosis, now I know that there’s nothing “wrong” with me. This is just who I am... It made me feel justified. It made me feel validated.” (Maddie)

Maddie also explained that it was not just validation for past experiences of bullying or being misunderstood that she now recontextualizes differently. Her own expectations of herself have changed, for the better: “It makes it easier for me to navigate life because now I know I just can’t navigate it the same way these people navigate it. I am now holding myself to my own standard instead of the standard of what I thought was ‘normal’”. Maddie reflects that, armed with her autism diagnosis, she will be “better prepared to handle life as an autistic person and not somebody who is autistic and trying not to be.”

In addition to the internal relief of pressure of relaxing the rigid standards to which she and the rest of the world had been enforcing, Maddie found that the people around her understood her better, and her social interactions became easier:

“After I recognized that about myself and after I kinda made peace with that and started living not as somebody trying to be normal and trying to constantly mask... I started living as somebody who accepted that about myself. And as soon as I did that and as soon as I communicated... with my friends and my support group... everything became significantly easier to deal with.” (Maddie)

Maddie’s experience aligns with literature on autism and disclosure in peer groups, with neurotypical peers giving more favorable impressions of autistic peers when autism was disclosed rather than when the neurotypical peers were unaware of the autistic person’s identity (Sasson et al., 2017). In the same study, when autism was not disclosed, neurotypical participants rated the autistic person less favorably than another neurotypical person in a social context. Maddie’s relationships improved when she shared her diagnosis, but before she learned she was autistic, she struggled in social situations, saying, “As a young adult... I started having to put myself in more social situations. I started having to go out and interact with the world and I was having a very, very difficult time doing that.” Maddie explains that this struggle to navigate social situations as a young adult prompted her research into autism, which was initially stymied by her prior belief that autism was “primarily found in children... I was under the belief that, oh, if you don’t get diagnosed as a child, then it’s, in a way, it’s way too late.” Even when her friend brought the possibility of her being autistic to her attention, Maddie dismissed the possibility, saying, “if I had autism, I would have been diagnosed as a kid, you know? I’ve never heard of

adults being diagnosed with autism, so I just kinda brushed it under the rug.” Her impression of autism as a childhood diagnosis is by no means unusual, although the delay in her understanding this critical facet to her identity took a toll on her experience transitioning into adulthood and attending college:

“That was my high school experience... not knowing that I had autism, and trying to live as a person without autism, and it just wasn’t working. And I think because of that, I was not really prepared to do a lot of the things like college... because I didn’t really know how to focus my energy on things.” (Maddie)

Rebecca spoke of a similar regret over her late diagnosis, saying that her college experience would have been drastically different if she had been armed with this critical information about herself.

“If I would have known back in the start of that... transition and going into college that I was autistic and had ADHD, I feel like it would have been such a different journey... That’s definitely where I feel like early diagnosis is kind of important because it really does... help you... understand yourself and be a lot easier on yourself... before knowing all this, I was so hard on myself to fit in and to be able to do what everybody else does and it was so stressful and... contributed to me... overworking myself and overstressing myself.” (Rebecca)

Despite the difficulties many participants experienced navigating accommodations, many still described access to these services as critical to their success in higher education. To be deprived of these necessary services due to a lack of diagnosis, as well as the added stress of not

understanding why things that appear to come easily to neurotypical peers are so difficult, is a substantial burden that could have been avoided through earlier identification.

Sarah, who was also diagnosed well past her college years, recalls similarly challenging experiences transitioning into adulthood without understanding this critical piece of herself. Sarah recollected, “That transition from high school to early adulthood was so challenging because I had no idea. I didn’t know myself at all... I didn’t know how to get from point A to point B, and I got into trouble through drinking, self-medicating... If I would have known this about myself then, maybe things would have been different.” Sarah didn’t realize what it was that caused her to struggle through this transition into adulthood, why she felt the need to self-medicate, until she began teaching:

“After my first year of teaching, I discovered that I was probably on the spectrum after attending a seminar for educators. I specifically worked with...kids on the autism spectrum. I transitioned over to the social service side of intervention after...understanding how I was going through autistic burnout through masking a lot at my job. And last year, I got the formal diagnosis of autism and ADHD.” (Sarah)

Sarah discussed multiple instances of masking and burnout getting in the way of her employment, an experience which unfortunately aligns with the realities of the job market for autistic adults. Wei and colleagues (2018) found that in a nationally representative sample of autistic young adults, autistic adults held a job for approximately 24 months. However, understanding why she felt unable to maintain the level of masking and demeanor she felt was necessary to present at work helped her find a more sustainable long-term career path.

Another component participants frequently discussed in their journey towards a diagnosis was the feeling of not understanding that their experiences were not typical. Ingrid, who was diagnosed fairly recently, explained, “I wish I had had an adult that I could have talked to...I didn’t know that I had seeing issues, writing issues, temperature issues until... this past year.” Ingrid went on to explain that she had not realized that other people didn’t struggle with the sensory issues she experienced, saying, “How am I supposed to know that’s not normal?”

Jamie, who received a diagnosis when they were a child but was not told by their parents that they were autistic until adulthood, reflects similarly on their experience navigating being autistic without being aware of their neurodivergence: “Because I didn’t know I was autistic, I didn’t know... what I needed.”

Again and again throughout the discussions of late diagnosis runs the theme of the need for self-knowledge, the essential nature of understanding what works best for each individual so that they can subsequently advocate for themselves. A late diagnosis can, therefore, lead to a journey of self-discovery that causes upheaval in a person’s life as they race to recontextualize a lifetime of experiences that were amorphous, without a set category or explanation. Receiving a diagnosis in adulthood is an enormous emotional upheaval, and for some, every bit as much a relief. It is the realization of missed opportunities for support, validation for confusion and struggle and tribulations endured, and the catharsis of realizing that feelings of alienation and difficulty navigating the world have a reason, a name, a recognizable origin. As Jamie wisely recommends, “For autistic people who are getting a late diagnosis... feel all the emotions you have, you know?”

Finances

While finances is a nearly ubiquitous struggle for transition-age youth beginning to achieve independence, with half of American adults demonstrating low financial literacy (Yakoboski et al., 2020), autistic individuals face additional challenges navigating finances in early adulthood. For instance, keeping and maintaining a job is challenging for autistic adults, although they often must do so to stay afloat financially, forcing autistic individuals to stay in work environments that are untenable for them. Nina describes her experience working as intensely stressful, saying, “I really need that job now...because everyone else is gonna get a job and then I'm not gonna have money and I'm freaking out...it wasn't consistent and I need consistency” (Nina). For Nina, the inconsistency and unpredictability of her work caused her constant anxiety, although she felt as though there was nothing she could do about this situation since she was dependent on her job to pay rent and keep herself fiscally above water.

Many other participants expressed financial barriers around achieving employment in the first place. Katherine, who related multiple experiences of being unable to maintain consistent employment, explained that she is located in a remote area and that her lack of transportation is a significant barrier to obtaining a steady position:

“I am unable to drive due to the way my brain processes information as well as the expenses that come with driving that I can't afford. But at the same time, my area has extremely poor public transportation and walkability. So, taking the little public transportation there is makes the commute up to three times as long as it would have been if I just drove.” (Katherine)

In this case, Katherine's inability to drive, in conjunction with the lack of resources to obtain private transportation, and the deficiency and inefficiency of public transportation all combine to create an impossible situation for her to navigate. Furthermore, due to her financial situation, Katherine is unable to move to a more easily accessible location: "I have nowhere else to go. I can't afford a house or apartment anywhere, because I don't even have any money to save or spend and I don't have any friends or family members who will let me move in with them" (Katherine).

Financial literacy, as well as lack of finances, was expressed as a major barrier in adulthood success by participants. Rose explains, "Not having anyone to teach you how to [pay] bills, like how to do money, is very hard. Because then housing is a whole other thing. How am I supposed to find a house when everything is four times my budget?" While financial literacy is an integral skill in adulthood, the lack of basic explanation of how to manage finances was seen as a barrier to being able to achieve goals such as independent living, maintaining a job or apartment, or even being able to complete daily living tasks.

While many young adults express lack of understanding around matters of financial literacy, autistic adults have lower financial literacy and more uncertainty around finances compared to non-autistic adults (Galizzi et al., 2023). This is unsurprising given that financial literacy is not commonly taught in high schools, and that transition programs and IEPs for autistic youth often lack a financial literacy component (Morrow & Dees, 2020). Alex, a singer, artist, and actor who struggled with navigating their finances after graduating from high school, lamented, "Suddenly, I have to [do] the paperwork. Suddenly, I'm financially responsible, you know?" (Alex).

Alex's experience with being suddenly thrust into a position of responsibility over one's finances with no preparation is compounded by their reliance on disability services for financial support, given co-occurring health conditions. Alex explains that the process of getting on disability was fraught with difficulty:

“I'm also on disability, so that helps with that. But the process of getting on disability was hellish, especially because I'm now an adult, and when you're an adult, you're expected to deal with all of it... I am fully convinced that getting on disability is supposed to be as impossible as possible, because if it were easy, then the government would have to give it to people who need it, and the government doesn't want to give help to people who need it... for all they care, we can die.” (Alex)

Underestimated/Infantilized

Autistic adults are traditionally infantilized, with even psychiatric professionals conceiving of autistic people as ‘child-like’, and the majority of autism research ignoring autism in adulthood and aging in favor of autistic children (Bosco, 2023). Autistic people are not immune to the effects of this infantilization, with many participants expressing feelings of frustration at being presumed incompetent and treated as younger than their age. Arlo expressed his frustration throughout his education at being consistently prevented from attempting to complete tasks on his own:

“I think what's... important is that the help should not be just thrown at the individual. We are the ones who are... asking for the help. If we ask for it, then...we're consenting to it. Non-consensual help isn't going to help... When I was in middle school, I had an

aide that they just threw at me...knowing that she was taking all my notes while I was taking them to, and she would stop me from taking notes, and it offended me because I was like, I don't need your notetaking to help me. I have my handwriting too." (Arlo)

This kind of infantilization was frustrating to Arlo and prevented him from taking agency over his own education, sending the message that Arlo was incompetent or incapable of taking his own notes. While Arlo agrees that help should be provided when asked for, it was both unproductive and undermining to be forced to withdraw his efforts to keep up in classes due to presumed incompetence. Kayden, an artist and Youtuber who focuses on mixed-media portraits, who explained that his parents did not assign him many responsibilities in childhood, recalled similar instances to Arlo: "Maybe it's possible [my parents] thought that maybe I would have a little more trouble doing those things on my own, so they would more or less go ahead and do them" (Kayden). While Kayden does not blame his parents for this assumption, he did discuss how this choice led to him learning certain skills later than he would have wished: "Our parents were surprisingly lax...there were a lot of basic things I honestly really didn't know until...college... even basic cleaning, I feel like I did not learn well enough until I was an adult" (Kayden). Nina had a similar experience with her family, saying:

"I wish [my parents] helped push me more...to do things. Instead of just being like, oh, she has this condition, she won't be able to do that. But they were supportive—but it's just that they would really baby me... I didn't like being babied all the time. I still do get babied." (Nina)

This attitude of infantilization followed participants beyond school and home into adulthood, where the protections of childhood were removed without either the instruction on how to navigate an adult world nor the confidence instilled through experience was present to bolster their success. Alex explains the strange and contradictory experience of aging out of childhood as a young autistic adult:

“I noticed that... it can be...your seventeenth birthday and they’re still treating you like you’re 12. And then it’s ... your eighteenth birthday and suddenly all the responsibilities are dumped onto you...everybody was like, let the adults take care of it. Now you’re the adult. How am I supposed to deal with that? Especially when... as an autistic child, even when you’re 17 it’s still like, because you’re autistic, you’re treated like you’re much younger... oh, it’s just a disabled child. It’s just an autistic child, protect them from the horrors of the world. And then, as soon as you turn 18, you’re an adult. It doesn’t matter if you’re autistic. Pull your weight.” (Alex)

Alex’s astute reflection paints a stark picture of the contrast between the low expectations of autistic young adults and the simultaneous enormous weight of responsibility of transitioning into a world without structures set up to accommodate them. This paradigm, as Alex explains, sets emerging autistic adults up for failure, as they struggle to navigate systems they have not been taught how to handle. At the same time, despite the barriers set in place, autistic adults have a right to presumed competence, and as Arlo explained, should not be subjected to forced help that they do not need. Offering support is not the same as presuming incompetence, and silence does not imply ignorance, as Jane explains:

“One of the things [that is important] is: presume competence. So I think that goes along with the infantilization. And I know I’ve experienced that, where they assume, because I look serious and I’m quiet that I don’t know what I’m talking about or I don’t know what’s going on or I’m incapable. When, in fact, the exact opposite is true. Just because I don’t present as a neurotypical person would, doesn’t mean I’m not competent.” (Jane)

The sentiment of frustration at the feeling of infantilization when a neurotypical person expects that an autistic person does not understand what is happening due to the autistic person reacting differently is one that was echoed among participants. Jane explained that she understands the misconception, saying, “I get it. It’s hard because it’s not like it’s visible. But I think that’s part of changing the image of what it means to be autistic, and actually listening to autistic people.” At the same time, participants expressed the importance of changing the narrative around autism and infantilization and underestimation. Arlo called for a change in public perception, saying, “I think the biggest thing we gotta understand is that, special needs... everyone’s gonna look down on them, and maybe they are going to feel more insignificant. And that’s definitely a big thing [that has to be] suppressed is that, there’s no concept of being belittled.”

The participants made clear that the support that they wanted was the support that they asked for. The goal was maximum independence, with important and needed support free of stigma. As Jane said, “I think what’s happening is autistic people are becoming extremely frustrated and not being listened to and by finally finding their voice and what works, and

wanting to shout it from the rooftops and say, no, you're wrong, no matter how many PhDs you have after your name, you're not listening...Listen to us." (Jane).

Ignorance and Indifference

Among the participants, there was a pervasive feeling that their struggles had been and would be met with ignorance and indifference. This sense of indifference on the part of people who could have helped, could have interfered to improve their lives, stemmed from childhood. Alex explains, "There was a lot of rampant bullying that went on right in front of the teacher's faces. None of the teachers did anything about it" (Alex).

Emily, who is now working towards blending her passion for theater and dedication to helping neurodiverse high school students into her career, recalls how her struggles went unnoticed as soon as her academic performance worsened. Other participants reported indifference on the part of their employers, with Jane saying, "Employers don't care, not really. They're not very understanding." Maddie seconded Jane's experience, saying, "The third job I had... they were not accommodating at all." Maddie explained that she was called out for being lazy although she was working as hard as she could.

"I just want you to know that this is what I'm struggling with... it's not like I'm being lazy. Sometimes I get overwhelmed and I need a minute. And they were the type of employer that was like, okay, but that's all an excuse... you're being lazy... they were of the mind that if your disability was not a physical one, then you didn't have one."

(Maddie)

Lack of understanding from employers is a commonly reported difficulty among autistic employees, with few autistic adults maintaining a job, and many businesses unwilling to hire autistic employees due to a fear of lack of productivity (Solomon, 2020). Jane, who worked at a social work company, a place she had expected to be met with understanding and accommodations, was instead treated with indifference on the part of her employers and coworkers:

“The mentality... buckle up, suck it up, you should be able to do what you need to do ... you’re not performing the way we want you to. So we’re gonna put you on an action plan which for a social work company who prides itself on, you know, mental health and child development, they sure had zero awareness about an employee being mentally ill and needing more. So I just feel like nobody cares. (Jane)

Sam, who went undiagnosed until adulthood and struggled academically throughout their primary years, recalled similar treatment:

“I kind of just winged my way through high school and didn’t do well. And the teachers didn’t seem to mind... they realized that... I wasn’t going to graduate because...I didn’t have enough credits for math or even like taking a foreign language... and they’re like, well, you took woodshop, so we’ll count that as math... I graduated with my class but I really don’t feel like I should’ve.” (Sam)

The teachers in Sam’s school discounted them as a lost cause, waiting until Sam was almost unable to graduate and then quickly sweeping the problem under the rug at the cost of Sam’s education. This indifference left Sam with a deep feeling that they did not deserve to graduate, as well as starting Sam off in life with a substandard educational experience. For autistic youth who already struggle to undergo the transition into adulthood, this lack of support can be devastating.

While participants reported receiving love and support from family and friends, they also recounted numerous instances of being met with indifference and cruelty from people in positions of power who could have taken the time to be kind, to understand, and to help.

Low Support Needs

The participants in this study were highly verbal, and many received late in life diagnoses of autism. As a result, most of the participants were labeled as having ‘low support needs’, in contrast to autistic individuals with lower verbal abilities or those who need in-home supportive services. Participants frequently expressed the sentiment that they fell in the unsteady ‘mild to moderate’ needs category, where services were either inappropriate to their needs or not offered for people who did not display higher levels of service requirements.

In addition to the lack of services for many of the participants’ levels of need, several participants discussed the role of masking in causing their existing service needs to be overlooked. Kyle explained that he “was able to mask so well that... I was able to just place myself out of special education services because I could blend in like a neurotypical person. But then coming to grad school and being more accepting of my autism and learning more about it, I’m realizing, I need some... accommodations.” Similarly to Kyle, Jamie recalled that they

struggled to keep up in a general education classroom, but was taken out of special education due to their intelligence:

“They were like, oh, this kid is very, very smart. Move me to general ed and apparently I no longer got the accommodations I needed, you know? From special ed... because they’re like...They don’t need accommodations. They’re fine! And then I’m placed in a classroom that I don’t know. The learning style is very different. The students never really talked to me... I always knew I was different. I always knew something was up. I always knew the way I functioned... I would have constant meltdowns... Bright lights would affect me. Noises would affect me. And I was told to just deal with it. Just deal with it, you know? And I would try to conceal, not feel. Not try to have meltdowns. Trying not to have ‘tantrums’.” (Jamie)

While intelligence is an important marker for determining educational placement, it is not the only consideration when placing a child and considering service needs. Jamie’s experience of being considered too gifted for special education resulted in Jamie not receiving necessary aides and accommodations in classes and experiencing ostracization at the hands of their peers.

School Social Interactions: Isolation, Sensory Overwhelm, Missed Social Cues

Participants encountered early difficulties with social interactions in elementary, middle and high school, but found that despite promises of a different social climate in higher education, difficulties navigating social situations followed them into college. Many participants came to college and higher education with a history of being isolated from their peers. Arlo, who attended a four-year college with aides and now works at a major research university caring for

lab animals, recalled: “In high school... I was much more tunnel vision, very shy, never knew how to make friends with people. Because I did not like socializing” (Arlo). Despite their hopes that college would provide a different landscape for making friends, when they reached college, many participants reported experiencing new obstacles in socializing. Nina explained that she would make and lose friends rapidly:

“When I went to the dorms my first year, I just felt it was so hard to make friends and go to social gatherings because I get a lot of anxiety in crowds and sometimes the noise is just a lot and it could... irritate me and trigger me into an episode. And it’s like, very loud in college so it was very hard for me at first to get into the swing of making friends... cause I would have friends for a little bit and then I felt like they’re irritated with me. Just like social interactions are very hard... I was used to... consistency at home and doing my routine.” (Nina)

Nina’s experience in trying to balance her desire to make friends with tolerating intense sensory discomfort and overstimulation was echoed by several other participants. Jane, who struggled to make friends in college and frequently felt overwhelmed by the hustle and bustle of the college environment and dorm rooms, recalls:

“[It] was hard, especially in college, because I didn’t go to parties. I didn’t drink. I was really socially anxious. So the social aspect of, oh, if you want to make friends, you have to go out and meet people. What? No. I’m just gonna stay in my dorm and eat microwave

Mac and Cheese and be sad. I mean, I was not about to go out and meet people at a party. It's loud. It's unfamiliar. It smells bad.” (Jane)

The sensory overwhelm was frequently in conflict with the participants' desires to meet new people and form friendships. Even when friendships were made, participants reported running into frequent conflicts and difficulties navigating unspoken social violations. Nina recalled, “Socially, I felt like I wasn't picking up on cues...I would sit down with my friend and it seemed like they didn't want me to be there. Or I wasn't invited to a party and stuff and I just felt like people were leaving me out and I felt like I was being annoying to them” (Nina). College socialization requires a certain degree of masking, or conforming one's behavior to a conventional standard, which Jamie, a graduate student studying education, found challenging: “In college, it was like you had to act a certain way, you had to be a certain way, you have to function in a certain way in order to succeed which did not help me at all” (Jamie).

While most participants who attended college reported struggling with the social climate in school, some participants had a positive experience, particularly those who bonded over shared interests. Sam, an aspiring filmmaker who received an autism diagnosis in adulthood, explained that they created strong friendships in college: “I had a good amount of confidence... when I was in college, I didn't seem to have any issues...with making friends. Because we were all kind of obsessed with film... the school overall was a pretty good experience for me socially.” Sam's experience speaks to a key aspect of friendships for autistic individuals. Autistic individuals are more likely to identify common interests in comparison to neurotypical individuals as a priority in creating and maintaining friendships, and is even used as a staple in

social skills interventions (e.g. PEERS; Laugeson et al., 2015; Black et al., 2022; Finke et al., 2019).

Importantly, despite their struggles to forge relationships in a college setting, all of the participants expressed valuing friendships. Jamie, who struggled to make friends in college, expressed that they “love meeting people. I’m very extroverted, but... I’m great at connecting with people, but I’m bad at... creating those relationships.”

Work Social Interactions: Unspoken Rule Violations, Exclusion, Bullying

The intricacies of unspoken social expectations followed participants into the workplace, where many were met with confusion at having accidentally violated certain workplace rules of decorum. Katherine, who attended college and has since spent her adulthood attempting to find steady employment, moving from job to job, explains that she has “unintentionally broken code of conduct rules due to poor social skills.” This sentiment was echoed among many of the participants, with Sarah saying, “jobs in general have been challenging for me. The social aspect of it and masking a lot is not the easiest for me.” Sarah, who cycled through many jobs in her early career in part due to the difficulty of adjusting her behavior to be appropriate in the workplace, explains her struggles in the early stages of her working life:

“The first professional job that I had... I didn’t have the kind of social boundaries that you know a professional job really requires. So I did make some mistakes, oversharing or maybe saying things that were a little inappropriate professionally.” (Sarah)

These types of social errors are rarely explained explicitly in a workplace. Few employers will instruct employees on their first day not to reveal private personal information to their new

coworkers, or instruct employees not to make public displays of emotion. However, these types of unwritten social rules are often not evident to autistic individuals, and are often learned through painful trial and error. Even when these social faux pas did not result in termination, participants reported that their coworkers often became uncomfortable of them, suspicious, or even outright hostile:

“People...just automatically know that there’s something off about you, that you’re a little weird and that you do things very rigidly and they’re like, hmm, she’s weird. I don’t know how I feel about this. And then they kind of like, in a way, backhandedly bully you. And then realizing as an adult in a work-like position... people still act like this outside of high school... having to get used to that is not fun... I was bullied throughout elementary school, middle school, and high school, and [I’m] thinking, okay, adulthood... everything’s still the same. And having to come to that realization is super disheartening because it’s like, will it always be like this?” (Emily)

This type of discrimination was commonplace among participants, with many reporting that their neurotypical coworkers or peers sensed they were different and began excluding them or treating them cruelly. Emily recounted her numerous experiences with exclusion at work with a heavy, exhausted tone, as though this was a reality she had long since become accustomed to: “People are once again alienating me at work, just like it happened in high school... I would call out all the time or I’d show up late because I had to really somehow convince myself to go...even your coworkers, there’s always going to be someone that just really doesn’t like you and will do whatever they can to just put you down for no reason” (Emily).

The unspoken expectations of a workplace environment includes a thorough, detailed, and mandatory social script that applies to a plethora of situations. While those who are equipped with this social script may not think twice about it, many autistic employees are at a disadvantage for not being taught these skills explicitly before starting a job.

Burnout/Meltdown

Autistic burnout is a phenomenon described by autistic adults that consists of exhaustion, incapacitation, and loss of functioning that can be debilitating for the individual (Arnold et al., 2023). Despite the fact that this phenomenon is widely known in the autistic community, there is very little research documenting or exploring its effects (Raymaker et al., 2020). Participants frequently described autistic burnout or meltdown as a significant barrier to achieving success in various domains of their adult lives, from work to friendships to school. Even daily living tasks were adversely affected by this meltdown. Maddie describes her experience of autistic burnout as an inability to complete most of her tasks and a single-minded need to self-soothe: “I just kind of did whatever I felt like I needed to do in that moment because anything else was really, really mentally exhausting” (Maddie). Emily, who had been fired due to the effects of burnout, describes her experience as an overflowing of emotion under unbearable pressure:

“All of this type of pressure... you do explode. And that’s happened to me multiple times where I’ve had a complete breakdown, burnout... where I just became someone completely different which led to me getting fired multiple times throughout the many years that I worked after high school. And I don’t think anything can prepare someone for having to deal with that level of emotion, of overflowing emotion, and also the loss of control over yourself because there were so many things pulling at you at once. And it’s

just like you're not even you anymore at that moment. It's a very scary place to be.”

(Emily)

Emily's meltdowns ultimately led to several terminations. While not all the participants were fired due to their burnout, it almost always led to some penalty or negative consequence. Rebecca, who ended up dropping out of college due to burnout, recalls that she “would be constantly stressed, constantly having these mental breakdowns because I would overload myself with these hard classes” (Rebecca). Ultimately, Rebecca ended up too overwhelmed to continue, saying that “Trying to juggle all of that... I ended up in a very... depressive state... I felt constantly burned out, because I wouldn't have enough time to...relax and recuperate.” Though Rebecca is now employed, she did express a desire to go back to school to advance in her field, although she feared returning due to her previous experiences.

This sense of defeat appears characteristic of autistic burnout. Participants explained that they felt unable to keep their head above water in their jobs, in their daily lives, with some struggling to take care of themselves during an episode of burnout.

A part of the self-acceptance journey that many participants embarked upon in adulthood or when learning of their autistic identity or receiving a diagnosis consisted of understanding their limitations and not judging themselves for them. Jamie recalls that they experienced many meltdowns around various aspects of their lives, from social interactions and masking to overwork.

While experiencing burnouts and meltdowns seemed to be a nearly ubiquitous experience among participants, time and practice had taught most participants how to handle this part of

their disposition and to organize their lives in such a way to prevent feelings of burnout from becoming overwhelming.

Executive Functioning

Executive functioning (EF) is a common challenge for autistic young adults. Although difficulties vary across individuals, common EF challenges include cognitive flexibility, phonemic fluency, and working memory (St. John et al., 2022). Many participants described struggling with poor EF skills and feeling that the pace of college or employment was too fast to keep up as they fought to keep their heads above water. Nina described her experience trying to keep up with a 10-week quarter system in college:

“I feel like the timeframe of it was really fast, and it took me a little bit longer to understand and I realized by the end of the quarter, that’s when everything finally clicked and I was like, why couldn’t it have been like this the whole time?” (Nina)

Similarly, Rebecca struggled with the pacing of higher education and with organizing her time efficiently, saying, “I was not prepared to... do all this workload... I just wasn’t taught how to properly study and... plan out my time efficiently... And I was like, okay, well if everyone else is doing it, I should be able to do it too.” Internal struggles when comparing themselves to other students or employees were common, especially among those who had not yet received an autism diagnosis and wondered, sometimes despairingly, why they were not able to keep up with the workload that their peers seemed to be handling without difficulty.

Although participants recalled struggling with comparisons and not understanding why they were having difficulty keeping up, retrospect afforded many self-compassion for their previous struggles. Participants explained that coming to terms with their strengths and limitations, as well as gaining a greater understanding of the way their brains worked helped to mitigate the effects of executive functioning difficulties, although this often happened later into adulthood. Participants frequently reported that they were not taught the organizational skills that would have helped them compensate. Maddie explained that when she was younger, she didn't have these skills: "I was not really as prepared to do a lot of the things like college and stuff like that because I didn't really know how to focus my energy on things."

This lack of preparation set many participants up for failure in college, where study skills and organization are assumed to already be in the toolkit of an incoming student. Jane, who described feeling total disorientation upon college entry, explained:

"It's like, you're on this road and you have no map. And everyone else seems to have a map in their hands or in their head, and they're doing fine. And you're still at the beginning of the road, like, what's happening? Which way do I go? I can't move forward. I don't know how... I think that's the hardest... the executive functioning piece and needing things to be very concrete and not so nebulous... It is really hard." (Jane)

This feeling, while upsetting and jarring to experience, is understandable given the structured nature of high school and the sudden jump from a supported environment to a self-directed learning experience. Rose describes this dissonance between the strict, timed blocks of designated time in high school and the nebulous, unstructured schedule of college:

“Not having a designated time set aside to do homework and to do outside work was really difficult, because... in high school, you had a study block... and so it was very easy to get your homework done in that time period. But going through college, you’re kind of responsible for making that time. And that did not happen, and it didn’t go well.”
(Rose)

This sense of defeat from changing one’s self-conception from that of a dedicated student to someone who is only able to achieve barely passing grades creates a learning environment wrought with additional strain and feelings of defeat. Sam describes their experience fading into the background after it became clear that they were struggling in school:

“I felt like it was my responsibility to do well in school and I knew that if I was struggling I wasn’t going to get help. I was going to get... reprimanded, or you know, hit or something. So it was not something that I felt like I could control or was doing on purpose. So yeah, I...didn’t do well. And the teachers didn’t seem to mind.” (Sam)

This experience of hiding their struggles and trying to compensate by flying under the radar followed Sam into adulthood, where they described getting into trouble at work due to struggling with executive functioning tasks such as time management: “I’d get fired because it was like the tenth time I showed up late to work and that’s just not okay...My time management skills are something that I still work on to this day and you know, things always change. So I have to constantly find new ways to stay on top of adulting” (Sam). The struggle with executive

function is one that does not leave autistic adults, although they find ways to cope and compensate. Emily, who now is successful in her job, explained that she found advice from her former teacher helpful.

Emily's teacher took the time to explicitly explain how to budget time, how to create a schedule, and how to portion out work so that it does not become overwhelming. These skills are learned, not innate, and autistic individuals can benefit from direct, clear instruction in studying so that they can arrive at higher education and employment armed with the skills they need to be successful. As Jane explains:

“I don't think an autistic person will ever have the executive functioning ability that a neurotypical person will. But if given the practice and the tools, I think it makes it a lot easier, so that when they go out in the world...even though they might not use it in the immediate time period they learn it, they file it away somewhere in their brain.” (Jane)

While autistic adults may struggle with executive functioning in ways that affect their work and education, they are not destined to be incapable of succeeding. Teaching study skills explicitly, rather than assuming that they are imbibed through osmosis in high school, is critical in promoting successful outcomes for this community of dedicated future students and workers as they forge their way into adulthood.

Disclosure

Many participants expressed fear of stigma or discrimination surrounding disclosing their autism diagnosis or autistic identity, saying, “Talking about disabilities, and being open about being neurodivergent, is still heavily stigmatized” (Kyle). While some kept their autistic identity

to themselves except for those closest to them, others were open about it. Nina recalled, “In college, I hid it because it felt like people don’t want to be friends with someone [who is] autistic... Now I just tell them, even on first dates, I’m like, ‘yeah, I’m autistic’, it’s awesome. So now I’m very open with it.” The openness Nina describes about her identity took time to develop. Alex described a similar attitude toward their autistic identity in college, saying, “Nobody really would have known I was autistic if I hadn’t said anything about it, which I did, because it’s just part of how I socialize. It’s something I’m very vocal about, because it’s not something that I want to hide from. It’s just not what I want my entire identity to be.”

On the other hand, some participants recalled experiencing more fear around disclosure. Sarah explained that part of her decision not to speak about it openly had to do with the culture in her area: “Talking about it openly in the workplace was really challenging. I live in the Midwest. I don’t appear to have autism and I think it was hard for a lot of people to understand.” Several participants spoke to regional or cultural stigmas surrounding autism. Sam, although they had not at the time received their diagnosis, recalled the fear that their family, who is Mexican and whose cultural norms discourage openness around mental health, would find out that they were struggling: “I would... feel ashamed or embarrassed and I would do my best to hide it and seem like... everything was okay.” (Sam)

Several participants spoke to the fear of consequences surrounding disclosure, with Zach explaining that although he chose to disclose his autistic identity to his coworkers, it was a decision fraught with anxiety: “I think the most difficult part was stepping out of my conference room to talk about my autism diagnosis to others, because I had that fear... are they going to bully me?” Although Zach was an adult when he faced this disclosure, the fear of bullying and persecution for his identity persisted. Participants spoke to how little they felt autism was

understood, and the fear of being thought of poorly or discriminated against by their peers. Alex, although they are now open about their autistic identity, still expressed fighting fears about disclosure to achieve that openness: “I wanted to start on a fresh page and not be known as the weird autistic kid. I wanted to be known as just, hey, that kid does good monologues. That kid’s not a half-bad singer.”

The fear that preconceptions would be formed based on an autistic identity was commonly expressed among participants. Kayden explains that, upon entering college, he was afraid to tell his peers that he was autistic for fear of being judged:

“I guess my biggest fear... was people thinking a certain way about me, like maybe they would think, oh, I’m not good socially because I’m autistic, but I feel like I would have been better off had I told them. But at the time, I think many people... thought of autism as like a– I mean, I don’t want to say disorder–but I think that’s kind of how they thought about it more then.” (Kayden)

This fear of disclosure led to Kayden not accessing the supports he was entitled to through the university. Although there were accommodations and support groups open to him, he did not take advantage of them at the time due, in part, to fear.

“[The college] did have a students with disabilities thing, but I think also at the time I was too afraid. I was trying to hide my autism a lot and was too afraid to admit I had a disability. And I thought I would feel better if I just didn’t really do anything about it and just kind of, you know, keep that to myself.” (Kayden)

This was not an uncommon story among participants, many of whom feared disclosing their autism status not only to peers, but to faculty and administration. Zach explains that he did not seek accommodations even though they might have been helpful out of fear: “I tried not to take my exams in a different support program in school, because I just didn’t want others to think that I was different.” Even students who were able to successfully obtain accommodations faced an additional barrier in communicating their needs to every new professor:

“Even given the accommodations, I still have a hard time approaching my professors and being like, hi! I have these accommodations... Do I deserve these accommodations? Should I be using these accommodations? Am I going to be seen differently for having accommodations? Those kinds of things. So I’m still trying to get over those ideas that are holding me back from really using my accommodations.” (Rebecca)

After braving the disability services office and obtaining the necessary accommodations, there is still the additional hurdle of disclosure; not just a one-time disclosure, but a repeated explanation of one’s individual needs and services every semester, to every professor and teaching assistant. This is a heavy, ongoing, daunting burden. Furthermore, there is the underlying fear that the person on the receiving end of the disclosure will treat the student differently, as Rebecca describes in her experiences with navigating accommodations. The result of this stigma is that many people do not explore the opportunities available to them, or may even shy away from receiving a diagnosis in the first place. Kyle, who now researches neurodiversity in academia, explains that “People don’t realize what’s available to support them.

It could be maybe because they had bad negative experiences. They might be reluctant to explore their identity.”

Despite the fear that many participants feel about disclosure, most agree that being open about their autistic identity is important– not only for living their own lives with authenticity and honesty, but for representation. Kyle explains, “There are neurodivergent people in academia, because of the stigma, they’re not necessarily going to want to put themselves out there... but it would help to have students out, to have people that are like us. It could motivate us to be successful.” Participants felt that creating a climate where there are many openly neurodivergent students and faculty may help remove the stigma from disclosure and create a safer place for students to share the entirety of their identities, and find acceptance.

What Works

Acceptance/Unlearning

Stigma against autism is prevalent, a facet of ableism that autistic individuals and families frequently encounter (Turnock et al., 2022). These prejudices are not exclusive to neurotypical individuals. Many participants reported internalizing ableist ideas and, as a result, masking to prevent judgment and discrimination. Ben, who works in the entertainment industry in music clearances, podcasting, music, and writing, explains, “There are a lot of ableist attitudes I had absorbed by osmosis, even being autistic myself... I’ve had a lot to learn.”

Through years of coming to terms with their autistic identity and embracing aspects of themselves they had striven to conceal, many participants recalled working to unlearn this internalized stigma on the path to self-acceptance.

“One thing I did was a lot of unlearning. Unlearning the masks that I’d put up to try and fit in with society. Unlearning the behaviors that I had learned to make myself seem more normal. Unlearning that freed up my stress, the part of my brain that processes stress, so that I could be stressed about things that mattered. And then there was a lot of effort put into unlearning my self-injurious behaviors and my self-detrimental thoughts... if you’re actively contemplating how you’re going to hurt yourself next, you don’t have any room to see yourself succeed.” (Alex)

Unlearning how to mask, how to conceal aspects of oneself from other people and how to embrace the things they once sought to repress, was a key aspect of almost every participant’s journey into adulthood. Self-acceptance was almost universally touted as the path to happiness, the avenue through which participants allowed themselves to embrace their full potential and pursue careers in their area of interest. Participants who consciously and actively worked towards self-acceptance reported learning about their strengths as well as their weaknesses, leading to a more positive self-image and better understanding of the way their minds work:

“To know yourself has really been the most liberating thing for me. It makes me feel the most free where it allows me to learn... I’ve always wanted to understand the world around me and the more that I understand myself, the more I can communicate...knowing how I work is really what’s changing everything for me... These past couple of years I’ve had to really search myself to understand how my mind works.... Trying and not succeeding at being like everyone else, kind of looking at my uniqueness and learning more about it has been really great.” (Sam)

While many regretted not being more open about their autistic identity, there were strong deterrents to doing so that were key facets of their childhood experiences. Zach recalls, “Autism is still not as understood, and dealing with the bullying from teachers and peers made high school really difficult and it made it hard to prepare and even accept that I was autistic.” Kyle similarly recalled that his own family was not supportive of his autism, saying, “In the family, I feel like it is hard for them to accept my diagnosis as being an autistic person. My mom told me that she regrets... telling me about the autism diagnosis.” Kyle’s early experiences did not encourage him to be forthcoming with his autistic identity, and on the contrary, encouraged him to mask and conceal his neurodivergence as much as possible: “My high school was too hostile of a place towards people who were neurodivergent. It wasn’t a safe place.”

A large part of acceptance for many participants came in embracing the strength that came with understanding the way their minds work. While stigmas surrounding neurodivergence lingered, many participants began to appreciate their strengths.

“Autism doesn’t make you different in the sense of, oh, you’re living in an entirely different universe and you don’t know what’s going on. That’s not what it is, you know. You’re living in the same world as everyone else. Your mind just works a little differently and innovation, invention, and progress requires people who think differently.” (Maddie)

Appreciating the strengths that come with having a mind that works differently than a neurotypical mind was a key step for many in arriving at self-acceptance and even celebration of

their own unique way of seeing the world. Jamie explains the beauty and joy they experience in the way they work: “Your brain functions differently but there’s beauty in it, I’m seeing beauty within it... I’m very passionate. I’m very organized... there’s tradeoffs here sometimes, but ehh, I love who I am, you know? I wouldn’t change it.”

For many, part of unlearning stigma around autism and ableism at large was coming to understand that it was not the autistic individual that was wrong or that needed to change to fit in, but the world that was not accommodating to the many incredible people and diversity it contained. Sam explained:

“The way you do things—it’s fine for you, right? There’s not one right way. There’s just living your life and then trying to figure it out like we’re all trying to figure it out. No one’s figured out the right path, there’s not just one. So I think that can help a lot of people... maybe in the future... our idea of what’s normal [will be] a much broader category. And that includes you and me and everybody. Because... I feel like the problem is maybe our society is just a little too narrow in its thinking or way we should act and do things.” (Sam)

This balance between working on changing oneself and working to change the world to fit them was a tension that several participants reported grappling with along their journey to understanding their autistic identity and their place in a larger society plagued with ableism and stigma against neurodivergence.

Finding Community

Along the road to self-acceptance for many participants, finding community was a key aspect of embracing themselves and their autistic identities. Kyle explains that finding community is integral to his wellbeing as a neurodivergent person in the world: “I think neurodivergent support groups are a huge thing, because we go through trauma and just having the space where you listen to each other or comment on experiences... a space where that stuff stays confidential...it’s very healing. It makes you know that you’re not alone because other people go through the same stuff.” Nina, who is active in her autistic community and advocacy groups, explains that autistic community is an invaluable aspect of her support system:

“[Autistic social support groups] are valuable to me because they understand my little quirks and sometimes I’ll make little joy noises and jokes and they’ll just be like haha, like I get you, I understand why you’re doing that. Or it’s like, oh, you don’t want to go there because it’s overstimulating so I totally understand. Compared to having a friend that’s not neurodivergent... they’d be like, why won’t you do that? So it’s like having friends that are on your level... It’s very hard for me to have neurotypical friends because I feel very judged by society, but having my neurodivergent friends, it’s fun.” (Nina)

Autistic social groups were described by many participants as safe spaces where they can unmask, where they are not moving through the world as a representative of the autistic community, where they are free to express themselves without the restraints typically imposed by neurotypical society. Some participants explained that they had trouble finding autistic

companionship outside of the contexts of advocacy, and valued spaces where they could socialize with other autistic people without an agenda

Many participants similarly found meaning in giving back to their communities. Kiki, who went to a special education high school and has postponed college for now while she works several jobs and internships to find her passion including acting, singing, and caring for children on the spectrum, shared, “I love helping people and being part of a really good community that helps people on the spectrum. And I just feel really good to be a part of it. And I’m glad that I can lend help to it.” Nina similarly expressed that she “[loves] teaching kids that have autism because I understand their struggles and how it could be different for them.” Kyle found himself connected to other neurodivergent researchers through his research and career in higher education, explaining that “In my work, I’m being connected with a bunch of cool people that are doing autism research, like neurodiversity research. And I feel like it’s making me dream big because...it feels good to become involved in advocacy, and my network is expanding rapidly.”

The journey to self-acceptance and unlearning ableism was taken, for many participants, through building autistic community and meeting other autistic peers that they admired, appreciated, and with whom they found reciprocal friendships. As Kyle explained, “Neurodivergent people just get each other.” In a world where participants expressed feeling confused, constantly told to conceal aspects of their fundamental being, and discriminated against for aspects of their deepest selves, finding a community of acceptance and freedom to be who they were was not only essential, but joyful.

Individualized Attention/Mentorship

Individual attention, so critical for development, was touted as one of the key supports appreciated by participants. From family members to teachers to counselors, a single individual

who truly saw the participant, cared about their wellbeing, and took a vested interest in their progress made a substantial difference in their trajectories. Sam describes how their mother was that person, demonstrating compassion and offering support for Sam throughout their life: “My mom is probably the person that has understood me the most throughout my life. There were definitely a lot of times where I saw that she really did understand. If I was struggling with sensory issues or if I was particular about certain things, she would listen to that” (Sam). Some participants described teachers in primary or secondary school, especially those with an understanding of autism:

“I had a teacher whose son was autistic... She knew how to handle me. She was very accommodating. She introduced new methods of learning to me... If I were to go to my school or principal and be like, hey, I think there’s something wrong, something’s going on where I’m not keeping up with the rest of the kids, his solution would just be to study more.” (Maddie)

The specialized attention and understanding of Maddie’s struggles was critical in helping Maddie navigate situations that naturally arose around understanding course material and sensory sensitivities. Maddie made clear that the lack of understanding from other teachers was not an indictment on them, rather, on a system of education that does not prepare teachers in general education to teach students with different ways of learning or those with disabilities. Often, it was not a teacher who was able to intervene, but a counselor or mental health professional.

Emily, who was not diagnosed with autism until adulthood and barely graduated high school due to medication prescribed through misdiagnosis causing a plethora of deleterious effects, expressed her wish that she had been able to meet with teachers and counselors who could understand her and who were able to advocate for her once her grades started to slip due to factors outside her control. This experience is sadly common, as Kyle explains, “That’s a problem with the...school system being underfunded and the high school counselors being burnt out because... they need to advise so many students, and they don’t have time to get to know you.”

Those participants who attended college reported a better experience with college counselors, professors, and academic advisors. College advisors were reported to help “create structure”, and inform what classes were best to take (Sarah). Those participants who reported getting individualized attention from counselors, professors, and faculty in higher education explained that it made a substantial difference, saying, “They were fantastic... [they did] it right” (Arlo). Even beyond the structure of formalized education, mentorship was considered a huge advantage in preparing for a career. Alex, who works in the entertainment industry in acting and singing, recalled how important that mentorship was to their career as they were starting out:

“It was through [music] that I met a lot of people who are still my friends to this day, and some really fantastic teachers... [with my mentor], we make all kinds of short films and music videos and stuff but I wouldn’t have half the success... I can have all these skills but not know a bunch of people in the [industry] who can conceivably get me work.”

(Alex)

This individualized attention and preparation by caring mentors was crucial to Alex's success in their career. Mentorship, while a staple of nearly every industry and specialty skill, is a component that emerged as particularly salient to the success and feeling of support and self-confidence among the participants. Participants expressed that they felt more competent, ready to take on new challenges, and navigate unprecedented situations equipped with thoughtful, understanding mentors. Furthermore, they suggested that mentorship for autistic young adults should stretch beyond the typical career or academic-oriented mentorship and should extend to life coaching, covering a myriad of personal and social topics as well as professional development.

Finding Your Passions/Strengths

Most autistic adults report having a special interest, passion or an intense focus on a specific topic (Grove et al., 2018). Ideally, special interests could be transitioned into a meaningful and fulfilling occupation, allowing autistic adults to bring their singular focus and dedication to a lucrative endeavor (Goldfarb et al., 2019). Participants often reported having a special interest and finding ways to channel their passions into careers or occupations. Jamie recommended that all autistic young adults find pride and express their interests: "Talk about your special interest. Go on and on about how much you love whatever you love. For me, I love Star Wars. I could go for hours about it!" Many participants gave similar advice to other autistic young adults, advising autistic individuals to lean into their passions and find ways to channel them into employment or educational opportunities:

"Think about the good times you've had, figure out why they were so good, and see if you can pursue whatever topic that good time was and then be like, oh my God, wait. I

can make that into a career? I could do that for the rest of my life? That sounds fantastic... Then, start doing research about what schools offer and then fully pursue it.”

(Emily)

Participants described their experiences pursuing their special interests and divulged the myriads of ways they were able to turn their interests into employment, hobbies, or passions that they could share with the world. Maddie explained how her special interest feels to her:

“What happens, I’ve noticed, is... I will watch a movie or I’ll play a game or I’ll listen to a song or something and whatever media that is gives me a feeling and then I’ll have it for the next three or four days, I’ll be completely engrossed in whatever feeling that was and write something that matches that feeling...I watched the Hobbit and I was like... I need to write a light novel about what it would be like to be a dwarf in the Hobbit... currently I’m writing a fantasy novel.” (Maddie)

Maddie explained that writing was an important part of her creative life and a means of expressing herself as she often struggles with spoken language, saying, “I do a lot of writing. I think writing is very therapeutic and I’m better with communicating with written communication more than verbal.” Alex describes a similar experience with music to Maddie’s urge to delve into worlds of imagination through writing, saying, “With all the emotion you can put into one melody, that’s sort of the whole idea behind why I write music. I’ve been studying music so long that I think in music, like the music that’s in my head directly correlates to what mood I’m in.” Emily similarly found her passion in theater, explaining that her first exposure to theater was

through her middle school production, and that ever since, performing arts became an integral part of her life: “ I just kind of fell in love with... creating something really cool. And I learned really important skills I didn’t have before, like time management, collaboration, being able to communicate properly when working in a team, and I feel like if I didn’t have that, I would have struggled a lot more in middle school and high school and adulthood.” Emily’s love of theater carried her into her current career aspirations; to use theater as a therapeutic outlet for children and teens with developmental disabilities.

Participants expressed that following careers based on their passions gave them confidence, excitement, and a willingness to push through the barriers that might typically have deterred them from pursuing employment. Their passions were often single-minded, deeply emotional, and beautifully sincere. While most participants spoke to special interests that had stayed with them through childhood and into adulthood, some found their niche later in life.

Alternative Pathways

Participants frequently endorsed taking an alternative route compared with a traditional four-year college straight out of high school. Several participants recommended taking time off after high school to think thoroughly about what they wanted to study (if anything), and to accrue some real-life experience:

“I would say, wait a little bit until going to college because I feel strangely overprepared in the best way possible for college... it comes a lot from having to deal with the many personality types that one does in the workplace... they were learning experiences.. For autistic people, it’s definitely better to have those skills already developing before getting to college.” (Emily)

Emily, who attended college later than most of her peers, found that the extra years gave her a focus, passion, and professionalism she would not have otherwise had. The benefit of her years of real-world experience working in the professional world allowed her to navigate social situations and zero in on her areas of interest quickly and effectively. Emily explained, “It’s a good idea to give yourself a few years to just think... So when you go to college, you don’t feel so lost and out of place. You actually feel a bit ahead of the game because a lot of other students are gonna be feeling a bit lost and all that.... We’re always gonna be someone out of place, slightly. That’s just how it is.” Sarah had a similar recommendation, explaining that she would recommend to autistic young adults and stakeholders to “[understand] that maybe not every single person is going to be able to go directly from high school to college and finish college within four years. Sometimes just having the real life experiences, and learning through failures too, is crucial for someone who is a hands-on experience type of learner.”

In addition to taking time off between high school and college, many participants endorsed attending community college rather than starting off at a four-year university. Maddie explained, “I chose community college because I wanted something not as intimidating... they were very accommodating. They were very understanding of everything.”

Community college was seen not only as a way to save money, but also as an avenue to give oneself time and space to figure out what participants wanted to study. Alex, who spoke highly of community college, explained that they felt the environment was much more welcoming to neurodivergent students compared with other higher education environments:

“I highly recommend doing community college first because it’s such a diverse population that teachers are oftentimes really willing to make adjustments for people who need them. And the student body is just so supportive and of all ages too. There’s people in their sixties and seventies in community college... one of the most popular students in the acting classes that I took. His name was [K] and he was a gay dad in his forties... and everybody loves him? Why? Because K... there was no reason not to love K. And that’s another thing. All different races, all different sexual orientations, all different neurotypes. Community college is a great place to be.” (Alex)

While community college was almost universally touted as an excellent transitional environment, several participants recommended or took alternate routes as well. Arlo mentioned vocational school as a strong alternative to building career skills without attending college: “Vocational schools! You can already have the entire amount of education for a job... as an electrician or a mechanic, doing anything... maybe it’s more effective. It’s faster.”

Regardless of the path they took, almost every participant stressed the importance of allowing autistic young adults to take an alternate, differently paced path into adulthood. They explained that the environment of a four-year college was often too fast-paced and not supportive of neurodivergence. They agreed that alternate paths, such as community college, vocational schools, and taking time off from high school to gain real world experience before entering into another educational environment was helpful in focusing their interests and promoting self-confidence and success.

Recommendations

High School Recommendations

Participants diverged greatly on how they remembered high school, with some reflecting fondly on their time but most having negative to traumatic experiences. Most felt that their high school failed to fully equip them with the tools for handling the subsequent stages of life, leaving them reeling in shock and feeling underprepared. Maddie shared, “In high school, they definitely should have prepared us for what it would be like socially, and even warn us about the drugs and stuff, because they didn’t really talk about it... They didn’t focus on the areas within a college you’d want to apply to clubs, resources, and what you could do to make an impact at the school.” Rebecca similarly felt as though high schools were not teaching the basic skills needed for success in higher education, saying, “Telling us about more of the differences between high school and college. Maybe taking the time to explain those differences, the studying process or the school process. Maybe even teaching us how to study, as basic as that sounds.” Beyond preparing the students for college, participants often felt that high school failed to prepare them for the tasks of living as an adult. Rose explained, “I think they could have taught me about money... What is the daily living expense for an adult... I think breaking down finances would have been so helpful.”

While participants acknowledged these things would have been helpful in their transition preparation, many acknowledged that there was not a system put in place for teachers and counselors to help neurodivergent students. Maddie expanded on this issue, saying:

“A lot of high schools, they focus on the kids as a whole, instead of recognizing that some of these kids may need certain things...if schools could learn to incorporate

different kinds of teaching methods instead of the same ones for everything, I think that would make it a lot easier because, unfortunately in situations like mine, there are a lot of kids who don't know that they have special needs or disabilities... and so they try really hard to keep up with people who don't have those same disabilities, and schools don't really take that seriously unless you bring in paperwork." (Maddie)

The rigidity of the current systems to only allot extra services to those who have disability documentation could lead to many undiagnosed teens and young adults being overlooked, who might have benefitted from an IEP or extra individualized attention. Kyle points out the difficulty in the lack of training teachers and counselors receive to assist this population of students: "I think part of the problem is that guidance counselors, I wish they had more support in advising their neurodivergent students, on how to set them up to get into a college, or how to get them ready for the whole college admissions process."

Kyle suggested that arming families with more information about autism and neurodiversity could be an easy way to promote better transitions in young adults, suggesting that high schools offer information on their websites:

"Posting links of research of the work that's being done by organizations that do research on neurodivergent students. If they're posting informative links on school websites, I know certain disability resource centers post those links on their website. But having a place on school websites that direct parents toward the research, so they could learn more about neurodiversity and autism and be connected with... the neurodivergent communities." (Kyle)

Overall, arming teens, young adults, and families with as much information as possible about what they will face when they graduate from high school, as well as endowing them with tools and strategies for time management, studying, financial literacy, and social skills for navigating new social situations such as professional environments were among the most common recommendations for high schools.

College Recommendations

While not all participants attended college, those that did recommended that colleges offer a wider variety of accommodations, more personalized attention, increased flexibility with assignments, autistic and neurodivergent community, and a Universal Design for Learning (UDL) approach in the classroom (CAST, 2018). All of these recommendations began with a request for college faculty and staff to have a greater understanding of the needs of neurodivergent students. Sarah opined, “Maybe if professors were able to understand that we do all have communication styles that are so different, maybe things wouldn’t be perceived as wrong.” There was a pervasive feeling that the different learning styles evinced by neurodiverse students were seen as wrong or, at the very least, inconvenient. Zach explained:

“When I went to community college, it was definitely a rocky road, and I feel like if they were more prepared to work with and help students with disabilities, it would have been so much easier. But there are some teachers and even support program specialists that I worked with, and they really did not want to make or help make the transition smoother... it was difficult. But if they truly had more staff that would be willing to help... even if it’s a short time or a long time transitioning, but instead of having them be

so negative towards us. I feel like that would completely change the game into helping autistics be more comfortable in their adulthood.” (Zach)

In addition to that individualized attention, recommendations frequently arose around clarifying expectations and laying out what accommodations were offered more clearly. Katherine recalled, “I wish my college had talked to me about certifications that I needed... I also wish that ahead of time, they had told me different vocational majors.” Services departments and university offerings are difficult to navigate, and individualized attention may be helpful in outlining what students are entitled to take advantage of within the university setting. Jane explained the types of tasks that could be supported with increased individual attention: “Here’s an example of your schedule. How are you gonna manage your time? Do you need a timer? Do you need to make a list? Those types of things. That would have been really helpful... having access to more therapists would be awesome.”

Within the classroom, participants expressed that more flexibility would be helpful. Sarah explained the importance of this latitude: “It would be nice to have a little bit of flexibility within the structure of a class or within the structure of an assignment... having autonomy with almost every single thing that I do in my life is so critical.” Similarly, Kayden explained that “extra time to turn in assignments... would have been a big deal.”

To make this shift to a more flexible learning environment, Jamie recommended shifting classroom design to a UDL style, a framework that provides multiple means of engagement, representation, and expression to appeal to the learning styles of diverse learners. Jamie explained how this could be implemented: “Create spaces that are based on universal design of learning. Creating accommodations for certain students with a disability is creating

accommodations for all people. Making sure education is accessible for everyone. Having more hands-on experiences, having more visuals.”

Rose, who was discouraged from returning to college after an accommodations officer asked her what accommodations she needed and she wasn't sure how to answer, suggested that for those with executive functioning difficulties who might have difficulty identifying their areas of need, there could be a 'menu' option of accommodations from which students could select their preferred accommodations: “They could have an accommodation list for me to circle things. That would be great.” In addition to the additional accessibility of accommodations, Rose suggested that having colleges provide areas of community for autistic or neurodivergent students would help promote feelings of acceptance and support among students: “I think it would be awesome for them to offer neurodivergent support groups or just get-togethers.”

Job Recommendations

Participants expressed confusion about expectations from their employers and organizations, as well as feelings of not being heard when they spoke up about needing accommodations. They requested the ability to go at their own pace without retribution or recrimination, assistance with transportation for those who could not drive, and preparation as to workplace structure and etiquette. Participants often felt confused about expectations from employers, even if they felt that they were doing well in their place of work. Emily recalled:

“The job that I just left, I remember my boss getting really upset with me and telling me, ‘you just do too much.’ And I was like, what do you mean...I feel like that's in comparison to previous employees but your previous employees aren't autistic...you're

telling me on one hand that I'm doing really well in my job and that you appreciate my work, but then I do too much." (Emily)

This confusion was compounded by the fact that Emily was saving the company money through her work, but was reprimanded for doing so, saying, "All the jobs that I've had... I had different ways of doing things and allowing me to do them the way I needed to do them in order to get the same result. And sometimes, I would figure out ways to save money for the companies I worked for but they were like, no. Do it the way it's written." The insistence of some employers of doing things by the book even if there was a more efficient way to complete the work that worked better for the participant was confusing and felt counterintuitive to Emily.

Overall, participants called for understanding from autistic employers, an open mind, an ability to listen to their needs for accommodation, and patience and clarity in educating them about protocols and workplace expectations.

Family Recommendations

For many participants, their families were a source of enormous support and encouragement. However, for many participants, especially those who were not diagnosed until later lives, their early experiences with their families led them to suggest alternative ways to support the next generation of autistic and neurodivergent young adults. To begin with, several participants wished that their families would have made a greater effort to understand autism and delve into research and literature to broaden their understanding: "My whole family was supportive and everything, and understanding. But I know for some families, they really don't understand the autistic side... they struggle with really trying to help their child out because they don't know how to help them" (Zach). Often participants reported that their families shamed

them without meaning to do so, out of a lack of understanding: “If they had done more research...that would have been very beneficial in just not feeling, I guess, defective throughout middle school and high school and into adulthood” (Emily). Similarly, Rose recalled feeling shamed by her family for being ‘dramatic’, although she had an autistic brother who received accommodations: “I think if they had not used words that were so non-intentional such as over dramatic, feelings being more accepted would have probably gotten me to where I’m at now a lot quicker had I had a family that didn’t look at my emotional dysregulation as like, oh, she’s just a dramatic girl.”

Participants advocated for openness and communication between parents and their autistic children, saying, “My parents could have... told me I was autistic and try to accommodate for what I needed. Like having a routine, having a schedule, having a fidget” (Jamie). Similarly, while Ben expressed understanding why his parents put him in ABA therapy as a child, he felt as though an increased understanding of the reality of ABA and neurodiversity might have helped his mother to choose a better option for him: “My parents could have... not put me in ABA... my mom just wouldn’t understand, because she would be like, well what were we supposed to do....you can force a child through this, but assuming there is even an actual use, [there is a] torture element of it.” Others reported that their parents held them to unrealistically strict standards which strengthened their sense of their own inadequacy when they inevitably failed to measure up:

“My parents are very hard people, like, oh, you gotta work hard and push yourself in order to succeed.... That definitely played into me overworking myself in college and stuff like that... even when I was struggling trying to juggle my job and school, they

would unfortunately not be very helpful, because they would be like, there's so many other people that can do it, why can't you? So unfortunately, I didn't have much help or support from my family, so I was just left to have all this pressure on me and then figure it out on my own down the line." (Rebecca)

Broadly, participants felt that it was important to both allow and encourage autistic teens and young adults to try new experiences, while remaining in contact to review strategies to cope with issues as they arose and brainstorm solutions to problems. This type of parenting may promote confidence, as autistic young adults feel safe to explore new options while knowing they have advocates ready to assist them. Sarah, spoke to the nuance of trying to strike this balance as well as attempting to reckon with contending with characteristics of neurodivergence in her child that she recognizes in herself:

"I think sometimes, parents who are neurodiverse and they maybe aren't diagnosed with anything, they will see aspects of your personality that remind them of themselves and then they'll really harp down on you. And that just causes a lot of inner turmoil. And I think it's just really important to step back and be present as a parent and really take into account that your child is an individual, and you'll have to shift your parenting style." (Sarah)

Participants acknowledged that there is not one perfect solution, and that families must constantly shift their approach to fit the individual needs of the autistic young adult as well as the

rest of the family. However, the major takeaway was similar to what every child wants: honesty, love, acceptance, and unconditional support.

“Tell your kids they’re autistic. Be honest and upfront with them. Try to support them. Not trying to make them hide their disability or hide their oddness. And celebrate it, too. Let them know, hey, yeah your brain and world functions differently but there’s beauty in that.” (Jamie)

While parents may not always get it right, participants expressed that the most important thing they can do is accept their child and teach them to celebrate their uniqueness, to embrace the parts of themselves that are neurodivergent so that when their children grow up and navigate the world as an adult, they are equipped with a full understanding of their strengths as well as their weaknesses. Although many participants were able to find self-acceptance in adulthood, they agreed that self-acceptance and self-love starts at home, in childhood, with parents who teach you that who you are is deserving of celebration.

Young Adult Recommendations

Participant recommendations for autistic young adults broadly surrounded how to plan for the future, finding friendship and community in adulthood, asking for help, and self-acceptance.

Young Adult Recommendations: Planning for the Future

In their recommendations to other autistic young adults starting the transition into adulthood, participants emphasized the importance of planning for the future while still remaining true to their interests and passions. Sarah explained that even when thinking

practically about making money or making strategic next steps, exploring interests and finding one's passion is critical in creating a successful life: "Testing out different interests is so important because I think so many people get caught up in, we have to do this and that and then that's the way it is. And then later on in your life, you're stuck in something you don't want to do." Kayden agreed, saying, "Be true to yourself. Take care of yourself. That's something I would have told myself in the past... Sometimes you think about the grand picture over the present moment, but I think it's better to focus on the present moment." Although participants encouraged emerging autistic adults to focus on the moment and their interests, they encouraged them to use visualization to try to use their current interests to build a path forward: "The best thing you can do is just visualize your future and think about what it will take to get there" (Ben).

Although participants suggested that autistic emerging adults focus on building their futures, they acknowledged that there may be some processing and grieving that this group of people may need to do to overcome trauma from their past, or to contextualize their lives, especially for those who received a late diagnosis. However, even amidst recollections of dark times, Emily suggested that there are seeds of passion and a way forward that can be gleaned from the work of processing the past:

"Reflect over all of your experiences and then see what are the highlights. Because you're only gonna see the really dark, sad moments and it's okay to cry about them when you're reflecting... you can mourn and feel sad for your younger self. I think that's a really important thing to do sometimes and just accept that kind of thing. But also, you do find those highlights and then you're able to start to analyze those highlighted parts of

your childhood and be like, why? Why is this so special? Oh, it's because of this... and that might be something that you can look into as a potential career.” (Emily)

Once young adults have found their passion and have goals that they are ready to work towards, participants suggested seeking out people who will help to guide them towards their goals, saying:

“Find a mentor. Find people that you want to work with and that will support you, because that makes all the difference. They might not necessarily know about autism. They might not necessarily know how to best support you, but they care about you, they want you to achieve your goals and they will be listening to you. And they'll actually want to learn more about neurodiversity.” (Kyle)

Overall, participants advised emerging autistic young adults to stay true to their interests, while taking concrete steps under the mentorship of someone in their chosen field, towards a career that fits their passions and talents.

Young Adult Recommendations: Finding Friendship

Many participants struggled with finding friendships and community in adolescence and young adulthood, and therefore directed encouragement and support towards the next generation of autistic adults in finding a community that would embrace them: “You're gonna be able to find a community and support of people who love you for being you” (Jamie). Katherine encouraged young adults to find or create social groups dependent on their interests so that they could find and bond with people with similar interests: “I know people with autism tend to have

really deep interests, join in social clubs based on your interest. If there's nothing out there for what you're interested in, maybe you can create your own." (Katherine)

Participants encouraged the next generation to be themselves, representing themselves authentically by playing with fidgets, bringing around stuffed animals or headphones, being upfront about their identities and needs, and allowing people who will be accepting and accommodating to find them instead of trying to cover up parts of who they are to fit in with people who are not willing to embrace them.

Young Adult Recommendations: Self-Acceptance

Overwhelmingly, the most common advice participants shared for emerging autistic adults was to love themselves and find self-acceptance: "You're going to learn to love every aspect of your identity: the good, the bad. Be patient with yourself" (Arlo). Participants reflected on the mistakes that they had made in reaching that point, and urged autistic young adults to be kind to themselves: "Just understanding yourself, taking the time, not beating yourself up, as hard as it is to not ruminate on the mistakes. I think, just allowing yourself the opportunity to make mistakes and know that's okay" (Sarah). Maddie explained the futility of comparing oneself to a neurotypical person, urging autistic young adults to understand that this comparison left everyone falling short:

"[Autism] is not something that is to be feared... When people don't understand something they're afraid of it. When there's a lack of understanding something, people are terrified of it...you're not weird because you have it... you're still a person deserving of patience, deserving of love. You're still somebody who needs a little help now and then and that's okay. Don't compare yourself to people who are not facing the same

struggles as you because that's not fair to you and it's also not fair to them, because sometimes there are things that people with autism can do that people who don't have autism can't." (Maddie)

Maddie, as well as other participants, encouraged autistic young adults to understand their strengths in addition to their weaknesses, and to see that having a neurotypical mind has its drawbacks as well; all human beings have strengths and weaknesses. Throughout this process, Rebecca recommends being kind, especially to those autistic young adults who may not yet have been diagnosed:

"If anybody feels like they're... neurodivergent, even before getting diagnosed... I feel like they should be very gentle and easy on themselves... they might not necessarily follow the same path, or fit in... Do what you need to feel like you're gonna be okay, and what will allow you to succeed... give yourself that grace." (Rebecca)

Chapter 5

Discussion

The aim of this study was to understand the perspectives of autistic adults reflecting on their transition into adulthood, what they found most and least helpful in navigating this transition, and what they think could have been done differently for future generations of autistic youth coming of age and finding their way. The participants in this study attended a variety of high schools, some mainstream and some special education or homeschooled, and took several different paths after graduation, from higher education to vocational training to starter jobs.

Participants ranged in age from 19 to 36, representing perspectives from various points throughout the transition to adulthood. The findings from this study spanned a wide variety of topics in the transition to adulthood, from the preparation the participants did (or more often, did not) receive in their high school for the next steps of life, the educational and vocational experiences they underwent after graduation, the barriers they faced, what worked for them, and their takeaways from that experience, as well as recommendations for institutions, family members, and autistic young adults.

The participants in this study experienced a wide variety of circumstances prior to their interviews. Many attended traditional four-year universities, while others came to higher education later in life, chose community college or vocational schools, or went directly into the job market after graduating from high schools. The participants had different socioeconomic backgrounds, although the population sampled was primarily highly resourced, meaning that only a narrow facet of the population may be represented by this study. Lower-resourced communities may have had entirely different post-graduation experiences.

As participants moved into adulthood and subsequent post-secondary educational and vocational experiences, they expressed the importance and burden of masking autistic behaviors and self-expression. While every adult by necessity uses some degree of masking to present a context-appropriate self-presentation to the world (Goffman's Self-Presentation Theory; Tan, 2014), masking for autistic individuals entails taking on neurotypical characteristics in social situations, such as maintaining eye contact or mimicking body language, or suppressing autistic characteristics, such as stimming and sensory discomfort (Ai et al., 2024). While there is some evidence to suggest that non-autistic people share certain characteristics of masking with autistic individuals, such as social mimicry or feeling tired from long periods of masking, these elements

of autistic masking are distinct due to the behaviors suppressed, the constancy of masking, and the stigma of the masked behaviors (Miller et al., 2021; Ai et al., 2024; Rehman et al., 2022). Masking in autistic adults appeared to have a greater toll on their mental and emotional wellbeing, with autistic masking leading to higher rates of suicidal ideation compared with non-autistic masking (Miller et al., 2021). Furthermore, masking stigmatized traits is linked both in autistic and non-autistic individuals with higher levels of depression, anxiety, stress, and identity difficulties (Ai et al., 2024), suggesting that for autistic individuals, constant masking of autism-specific stigmatized behaviors (e.g. stimming) may take an additional, heavy toll.

Masking was often something participants reported being taught, or learning as an adaptive coping mechanism, at a young age, and which was required for success in professional or collegiate environments, despite a heavy toll of exhaustion and even losing one's own identity in the creation of a false persona. This reported experience aligns with the McAdams theory of personality development (McAdams & Olson 2010), in which goal-oriented personality traits are layered on top of self-definition as children enter middle childhood and adolescence. For these participants, their natural behaviors were overridden with the need to camouflage certain elements of their personalities as they entered middle childhood, beginning to define themselves along the lines of their false personas. These overlays were then deconstructed in another critical developmental milestone of personality development, emerging adulthood, when participants found that this artificially constructed overlay was either no longer serving their needs, was exacting too high of a cost, or no longer aligned with their self-defined goals and narrative identity (McAdams & Olson, 2010). These findings correlate with other reports from autistic participants on the experiences of masking, with many reporting that constantly masking was exhausting and left them feeling alienated from their authentic selves (Miller et al., 2021).

Research on autistic masking is still relatively rare, with masking mostly existing as a colloquially discussed phenomenon in the autistic community.

Additionally, masking appears to be a somewhat gendered behavior in the autistic community, with a systematic review of masking in autism finding that masking is more common among autistic females than autistic males (Alaghband-Rad et al., 2023). This may be due to a variety of factors, and as there is little research on non-cisgender autistic individuals and masking, it is unclear the degree to which masking behaviors may manifest for the entirety of the autistic community. Future research may examine the different behaviors of masking depending on context, as well as the toll and consequences of doing so for autistic adults of varying gender identities.

While the heavy toll of masking was often mentioned by participants, there is disagreement even in the autistic community about the benefits and detriments of masking. Masking can be seen both as a burden and as an essential asset to succeeding, particularly in more socially rigid environments such as the workplace (Miller et al., 2021). The balance of teaching an individual to mask certain behaviors in environments where that person might deem behavior regulation to be necessary (i.e. in the workplace) and in encouraging society to move towards a more accepting and neuro-affirming framework of accepting a variety of behavioral expression was something participants spoke to and seemed to continually consider in their quests to present themselves authentically in their lives and achieve success in the workplace. Future studies should examine this dichotomy, as well as investigating potentially tenable balances that optimize both the individual's feelings of freedom and ability to move through the world comfortably.

Participants, particularly female and nonbinary participants, described their experiences of late diagnosis in adulthood, or discovering later in life that they were autistic. Many expressed feelings of regret or sadness at not knowing this critical information about their life experiences earlier. Female participants shared that they felt resentful that their gender prevented them from being identified at an earlier date, and getting the help their male relatives on the spectrum received as children. Furthermore, female participants described experiences of navigating friendships and romantic relationships that were particular to their gendered identity. While not many participants discussed their experiences with romantic relationships, several female participants described negative experiences with dating and sexual experiences, saying that they felt as though they were unable to perceive malintent from partners, and were further unable to ascertain the negative effects of romantic or sexual abuse on their own bodies and emotions due to alexithymia. While relationships were not the primary focus of this study, autistic adults and romantic and sexual relationships is an understudied and critical area of research for promoting health and wellbeing in adulthood. Future research may further investigate the experiences of autistic women and romantic and sexual relationships, both positive and destructive. Future social skills interventions may also develop a focus on identifying healthy and unhealthy aspects of relationships, as well as protecting oneself from mistreatment and abuse, building a support network, and identifying avenues of escape in abusive situations.

Participants spoke of their experiences with accommodations in the school and workplace, the helpful nature of the supports they received, as well as the difficulty of the obstacles that must be overcome to obtain them, citing struggles with disability offices, cumbersome paperwork, and inability to communicate with faculty. The difficulty in accessing accommodations and the many barriers participants reported encountering in their quest to obtain

them also parallel the experiences many autistic college students have reported in prior research on this topic (e.g. Wolpe, 2024). Given the frequency with which difficulty obtaining accommodations arose, institutions may consider a revision of accommodation policies. Offering ‘open accommodations’, or providing accommodations for anyone without requiring paperwork, may be a way to remove barriers from those struggling to navigate the disability services offices.

There is existing research on the preferred accommodations autistic adults select when given a menu of options, the most common of which is extra time on tests, copies of notes, and priority registrations (Accardo et al., 2019). Inquiries into autistic college students’ preferences demonstrated that providing autistic community, individualized mentorship, and neurodiverse spaces may be helpful complements to traditional accommodations offered by universities (Sarrett, 2018). Additional supports such as colleges implementing a transition program for incoming freshmen, residential life supports, and increased vocational training have been similarly cited by autistic students as potentially helpful offerings most colleges do not provide (Widman & Lopez-Reyna, 2020). Future research may examine which avenues of providing accommodations as well as which type of supports prove most successful for rates of utilization among autistic students, as opposed to continuing with the current system of requiring the autistic individual to self-advocate and complete additional hurdles to receive necessary support.

Finally, participants shared the wisdom of their lived experiences to inform autistic young adults just beginning this transition on how to plan for the future, finding friendship and community in adulthood, asking for help from trusted allies, and reaching a place of self-acceptance. While research on the journey of self-acceptance in autistic youth is rare, extant research suggests that both self-acceptance and acceptance from those closest to the individual is imperative to achieve well-being during this tumultuous transition (Lee et al., 2021). Future

research may focus on community-based education to raise autism understanding and acceptance to prevent each autistic individual and their families from undergoing that journey in a vacuum. As Kyle shared, “It is key to surviving as a neurodivergent person or as a person that identifies as being disabled in the world, just having support networks.” No young adult thrives on their own. Building a strong support network and community with family, friends, mentors, and other neurodivergent peers is critical to bridging the gap into adulthood.

Limitations

This study has several limitations. Despite a substantive sample size for a qualitative interview study, these interviews serve as a microcosm of the experiences of a much larger population and cannot necessarily be generalized to the experiences of the community as a whole. While interviews are not intended to provide generalizability, it is important to note that the interviews presented in this study represent only a subsection of the experiences of the participants and should not be extrapolated to the experiences of non-participating autistic adults. The sample was majority White and English-speaking, which excludes a largely underserved non-White and non-native English-speaking subset of this population with varying experiences. Furthermore, due to the nature of Zoom interviews, perspectives of nonverbal or minimally verbal autistic individuals could not be incorporated into this study, a significant limitation as a large portion of the autistic community uses assistive communication devices or does not communicate through spoken language. While this study did not explicitly prohibit anyone who was autistic and over the age of 18 from participating, the format itself was exclusionary. Future research may consider offering alternatives to interviews such as written surveys or in-person meetings to allow for increased accessibility and a subsequent broader array of potential participants and viewpoints, as well as translators or researchers who speak multiple languages.

The age range of this study was quite broad, including individuals from ages 19-36. While this age range was included to capture the spectrum of experiences from across the transition to adulthood, retrospective bias may be a confounding factor in older adults recalling their experiences at a much younger age. Retrospective recollection may be subject to a positivity bias, as well as decreased accuracy as time passes (Skoronski, 2010; Colombo et al., 2020). Future research may consider recruiting a narrower range of ages restricted more closely to times participants are experiencing the most transition-related life events (e.g. ages 19-24).

The nature of recruitment further narrows the population to autistic individuals present on social media or involved in organizations that would connect them to the primary researcher. These participants are not necessarily representative of the larger autism community, and therefore their experiences should not be taken as representative of the autism community as a whole. Autistic individuals who are active on social media and are comfortable reaching out to an unknown researcher to volunteer to participate in a study are likely reasonably social and outgoing as well as skilled in scheduling and arriving at a set date and time, traits which may not be representative of the autistic community more generally, who have noted difficulties in social skills and executive functioning. Future research may consider additional alternate avenues of recruitment, such as visiting various autism communities both online and offline to recruit a more varied sample.

Finally, while general demographic information was included as to participants' broader characteristics (e.g. gender, age, ethnicity, type of high school attended, and primary language spoken), more detailed background on their families of origins, socioeconomic status, educational and vocational trajectories, and types of college attended were not systematically collected. Future qualitative research may consider collecting a more thorough demographic and

personal history prior to interview to help contextualize participants' experiences and allow for a more detailed description of each participant, which would allow readers to place the participant's experiences in the context of their backgrounds.

Conclusion

The goal of this study is to understand the perspectives of autistic adults in the transition into adulthood. The scarcity of literature in the topic of autism and transition to adulthood, as well as the paucity of research exploring autistic adults' perspectives on their own lives in experiences, creates a critical gap that this study aims to address. The findings from this study will inform future qualitative exploration of autistic adults, as well as provide information for the systems currently in place to support autistic emerging youth transitioning into adulthood with invaluable insight into how to improve the process for the upcoming generation. This study is intended to represent a jumping off point from which researchers can collaborate with the autistic community, both as participants and as co-facilitators in research design, to center the priorities and desires of the autistic community in designing interventions to promote better quality of life and success in various domains of adulthood.

Appendix

Table 2. Code Frequency Count

| | Emily | Maddie | Nina | Rebecca | Katherine | Sarah | Ingrid | Sann | Zach | Jane | Keenan | Alex | Kiki | Kayden | Ben | Arlo | Jamie | Totals |
|-----------------------------|-------|--------|------|---------|-----------|-------|--------|------|------|------|--------|------|------|--------|-----|------|-------|--------|
| Barriers to Success | 15 | 18 | 11 | 15 | 13 | 13 | 15 | 19 | 6 | 28 | 15 | 10 | 0 | 5 | 7 | 7 | 16 | 213 |
| Burnout/Meltdown | 2 | 4 | 1 | 5 | 1 | 4 | 1 | 1 | 1 | 4 | 0 | 1 | 0 | 1 | 0 | 1 | 4 | 31 |
| Disclosure | 0 | 1 | 1 | 1 | 0 | 2 | 1 | 0 | 3 | 0 | 4 | 1 | 0 | 2 | 0 | 0 | 0 | 16 |
| Executive | | | | | | | | | | | | | | | | | | |
| Functioning | 2 | 1 | 1 | 5 | 2 | 0 | 2 | 5 | 0 | 7 | 2 | 2 | 0 | 0 | 0 | 0 | 1 | 30 |
| Finances | 1 | 1 | 2 | 1 | 5 | 0 | 2 | 1 | 0 | 0 | 4 | 2 | 0 | 0 | 4 | 0 | 0 | 23 |
| Indifference | 2 | 2 | 1 | 0 | 0 | 0 | 0 | 5 | 2 | 5 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 19 |
| Lower Support | | | | | | | | | | | | | | | | | | |
| Needs | 0 | 0 | 1 | 0 | 0 | 0 | 4 | 1 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 1 | 9 |
| Social Skills | 2 | 3 | 3 | 0 | 2 | 2 | 1 | 5 | 0 | 8 | 1 | 0 | 0 | 0 | 3 | 2 | 5 | 37 |
| Timing of Diagnosis | 6 | 6 | 0 | 3 | 0 | 5 | 4 | 0 | 0 | 1 | 2 | 0 | 0 | 0 | 0 | 0 | 5 | 32 |
| Underestimated/Infantilized | 0 | 0 | 1 | 0 | 3 | 0 | 0 | 1 | 0 | 3 | 0 | 2 | 0 | 2 | 0 | 4 | 0 | 16 |
| Educational/ | 3 | 2 | 11 | 4 | 2 | 6 | 6 | 3 | 5 | 5 | 12 | 4 | 0 | 4 | 3 | 17 | 17 | 104 |

| | | | | | | | | | | | | | | | | | | |
|------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|----|
| Vocational | | | | | | | | | | | | | | | | | | |
| Experiences | | | | | | | | | | | | | | | | | | |
| Accommodation and | | | | | | | | | | | | | | | | | | |
| Special Services | | | | | | | | | | | | | | | | | | |
| Experiences | 2 | 1 | 5 | 3 | 1 | 1 | 1 | 0 | 1 | 3 | 9 | 2 | 0 | 3 | 1 | 6 | 5 | 44 |
| Masking | 1 | 1 | 1 | 0 | 0 | 0 | 2 | 3 | 3 | 0 | 3 | 1 | 0 | 0 | 2 | 0 | 9 | 26 |
| Partying/Drugs | 0 | 0 | 1 | 0 | 0 | 2 | 1 | 0 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 5 | 0 | 12 |
| Routines and | | | | | | | | | | | | | | | | | | |
| Change | | | | | | | | | | | | | | | | | | |
| | 0 | 0 | 4 | 1 | 1 | 3 | 2 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 6 | 3 | 22 |
| Life Skills | | | | | | | | | | | | | | | | | | |
| Preparation | | | | | | | | | | | | | | | | | | |
| | 2 | 3 | 2 | 2 | 4 | 1 | 1 | 1 | 2 | 1 | 2 | 7 | 4 | 5 | 3 | 1 | 5 | 46 |
| Constructive | | | | | | | | | | | | | | | | | | |
| Experiences | 1 | 2 | 2 | 0 | 1 | 1 | 0 | 1 | 2 | 0 | 1 | 3 | 4 | 3 | 3 | 1 | 0 | 25 |
| Lack of Preparation | 0 | 0 | 0 | 2 | 2 | 0 | 1 | 0 | 0 | 1 | 1 | 2 | 0 | 2 | 0 | 0 | 2 | 13 |
| Unhelpful | | | | | | | | | | | | | | | | | | |
| Experiences | 1 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 3 | 8 |
| Recommendations | | | | | | | | | | | | | | | | | | |
| College | | | | | | | | | | | | | | | | | | |
| Recommendations | 0 | 0 | 0 | 1 | 1 | 2 | 1 | 0 | 0 | 3 | 1 | 0 | 0 | 1 | 0 | 0 | 5 | 15 |

| | | | | | | | | | | | | | | | | | | | |
|-------------------------|----|----|----|---|---|---|---|----|---|---|----|----|---|----|----|---|----|-----|--|
| Family | | | | | | | | | | | | | | | | | | | |
| Recommendations | 1 | 1 | 1 | 1 | 3 | 2 | 1 | 0 | 1 | 1 | 2 | 1 | 1 | 3 | 2 | 0 | 6 | 27 | |
| High School | | | | | | | | | | | | | | | | | | | |
| Recommendations | 1 | 1 | 1 | 1 | 1 | 1 | 3 | 0 | 1 | 0 | 2 | 1 | 1 | 0 | 0 | 0 | 3 | 17 | |
| Job | | | | | | | | | | | | | | | | | | | |
| Recommendations | 2 | 1 | 2 | 1 | 2 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 2 | 0 | 1 | 0 | 0 | 13 | |
| Young Adult | | | | | | | | | | | | | | | | | | | |
| Recommendations | 3 | 2 | 2 | 4 | 4 | 2 | 2 | 0 | 1 | 1 | 3 | 5 | 1 | 3 | 3 | 7 | 8 | 51 | |
| <i>Asking for Help</i> | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 5 | |
| <i>Finding</i> | | | | | | | | | | | | | | | | | | | |
| <i>Friendship and</i> | | | | | | | | | | | | | | | | | | | |
| <i>Community in</i> | | | | | | | | | | | | | | | | | | | |
| <i>Adulthood</i> | 0 | 0 | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 2 | 7 | |
| <i>Planning for the</i> | | | | | | | | | | | | | | | | | | | |
| <i>Future</i> | 3 | 0 | 0 | 0 | 3 | 1 | 0 | 0 | 0 | 0 | 1 | 2 | 0 | 1 | 3 | 0 | 1 | 15 | |
| <i>Self-Acceptance</i> | 0 | 2 | 0 | 3 | 0 | 1 | 2 | 0 | 1 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 3 | 14 | |
| What Works | 16 | 10 | 11 | 7 | 9 | 6 | 7 | 15 | 9 | 3 | 31 | 15 | 7 | 10 | 11 | 8 | 12 | 187 | |
| A Different Route | 3 | 1 | 1 | 2 | 0 | 1 | 0 | 0 | 2 | 1 | 1 | 2 | 1 | 0 | 0 | 1 | 0 | 16 | |
| Acceptance/Unlearn | | | | | | | | | | | | | | | | | | | |
| ing | 1 | 4 | 0 | 1 | 0 | 1 | 3 | 6 | 2 | 0 | 8 | 2 | 0 | 1 | 3 | 2 | 2 | 36 | |

| | | | | | | | | | | | | | | | | | | |
|---------------------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|------|
| Advocacy | 1 | 0 | 3 | 0 | 0 | 0 | 1 | 0 | 3 | 0 | 3 | 0 | 1 | 1 | 1 | 0 | 5 | 19 |
| Finding Community | 2 | 1 | 4 | 1 | 2 | 1 | 2 | 2 | 1 | 0 | 13 | 2 | 1 | 1 | 0 | 0 | 3 | 36 |
| Finding Your | | | | | | | | | | | | | | | | | | |
| Passion/Strengths | 5 | 2 | 1 | 2 | 2 | 1 | 1 | 5 | 0 | 0 | 0 | 4 | 0 | 1 | 1 | 0 | 1 | 26 |
| Individualized | | | | | | | | | | | | | | | | | | |
| Attention/Mentorshi | | | | | | | | | | | | | | | | | | |
| p | 2 | 1 | 2 | 1 | 1 | 2 | 0 | 1 | 1 | 2 | 5 | 4 | 2 | 3 | 4 | 5 | 1 | 37 |
| Starter Jobs | 2 | 1 | 0 | 0 | 4 | 0 | 0 | 1 | 0 | 0 | 1 | 1 | 2 | 3 | 2 | 0 | 0 | 17 |
| Totals | 50 | 43 | 45 | 42 | 47 | 36 | 41 | 40 | 29 | 46 | 73 | 55 | 21 | 39 | 38 | 41 | 85 | 1387 |

Young Adult Transition Interview Questions

1. Could you describe what you doing now in your adult life?
 - a. Career/education
 - b. Living situation (dorm life?)
2. Could you tell me what you remember about preparing for adult life/college/next steps in high school?
3. What did you do in high school that you feel best prepared you for [*college, vocational school, internship/job, independent living—ask whichever applies to the participant*]?
4. What was most difficult for you about transitioning from high school to [*next steps fill in here*]?
5. Was there anything about this transition that you remember going well or being easy?
6. What do you think might have helped make that transition easier?
 - a. Things your school could do
 - b. Things your job/college/internship/support staff could do
 - c. Things your family could do
7. Is there any advice you would give to a young autistic adult who is about to graduate from high school?
8. Is there anything else you'd like to share on this topic?

Figure 1. *Interview Protocol*

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